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13. ABSTRACT (Maximum 200 Words)
The goal of this program is to develop and recommend a model of care that enhances the quality of life for DOD children with life-threatening conditions and their families. Our strategy is to maximize current benefits and coordinate medical care with existing community resources and services, tailored to support the family's specified needs and requirements. The first year of work focused on a feasibility study to gather data on the intent, interpretation and implementation of the benefit; status of service delivery; available resources through the Military Health System, contract providers, community and other government agencies; and to conduct an assessment of needs of families. A distinct research protocol was designed to use individual interviews and focus groups to determine family and provider needs. The benefits likely to be used by military families and their children were analyzed. A data assessment collection tool has been designed to capture descriptors regarding community resources. The plan is to web enable the database in order to provide maximum availability and accessibility to the various potential users. An existing education curriculum for providers, Initiative for Pediatric Palliative Care, developed by the Education Development Center, was selected as one that best aligns with the CHI PACC® model.

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INTRODUCTION:

The focus of this project is to conduct a feasibility study to explore how pediatric palliative care has been implemented in the medical community, particularly through the use of Medicaid waivers and the application of the principles promoted under the Children's Hospice International Program of All Inclusive Care (CHI PACC®) goals and standards; to identify and analyze issues relevant to providing pediatric palliative care within the Department of Defense (DoD) Military Health System (MHS); and to make recommendations and provide strategies for implementation of such a program that would enhance the quality of life for these children with life-threatening conditions and their families. This program model will be designed to integrate palliative care interventions with therapeutic approaches to disease management from the time of diagnosis and to provide a smooth transition to hospice care when the child and family is ready to make that choice. The strategy is to maximize current benefits and coordinate medical care with existing military and community resources and services, tailored to support the child's and family's specified needs. Clear identification of required resources and services that are not available will allow the model to focus on requirements that are unmet. The first and second years of work have concentrated on an assessment of needs as perceived by families and healthcare providers in the MHS; an analysis of the benefit and the current status of service delivery as it relates to the goals and principles of pediatric palliative care; and the available resources through the MHS, TRICARE managed care support contract providers and services, and resources through the community and other federal, state and local government agencies. Steps have been taken to ascertain the key aspects of a pediatric palliative care plan that provides important elements of such a program, primarily coordination, continuity and a continuum of care, and that would be feasible and achievable within the existing benefit and structure of the MHS. This report will discuss the findings to date and outline the remaining aspects of research and analysis needed to make recommendations, implement a pilot project, and develop appropriate outcome measures that would evaluate the cost and effectiveness of the program.

BODY: Research accomplishments related to objectives in the Statement of Work.

USUHS research regarding needs assessment

Relevant objective in SOW: Objectives 1 & 2 (FY 03 proposal), Objective 1 (FY 04 proposal)

To date, four sites have given full Institutional Review Board (IRB) approval for family and provider needs assessment focus groups and interviews. Recruitment and interviews have begun for families and providers from each of these sites. (Appendix 1)

Needs assessment: Advisory groups

Relevant objective in SOW: Objective 1(FY 03 proposal), Objective 1 (FY04 proposal)

Parents invited to participate in the advisory group have been part of a similar group format for a previous study. Family members have been recruited from a group of parents of children who are currently ill with a life threatening illness, who have recovered from their illness or who have died from their disease. Their role in this project is to serve as research collaborators in a parent

advisory group that will review focus group and interview questions for use with newly recruited parents and health care providers and to adapt a quality of life survey for caregivers for use with this population. The purpose of their input is to insure that the data collected from families through the focus group or interview process will accurately reflect their varied experiences. In the future, the advisory group will assist in the interpretation of study data and the development of models for care delivery and a program evaluation tool. As the project progresses, additional parents, who have participated in needs assessment focus groups and interviews, may also be invited to join the advisory group.

Three advisory group meetings have been held to date. The first meeting served to familiarize the parents with the project and their roles as research advisors. The parents each shared their children's stories. Each story provided an insight into the needs of these families and the difficulties they face as they struggle with the child's medical condition and traverse the military health system. These needs were then analyzed and developed into themes. The group then discussed the Himelstein definitions of disease trajectories and determined which category was relevant to their child. (Discussion of these categories can be found under eligibility criteria.) A Tentative Schematic Diagram of Care (Appendix 2) was presented for the group's evaluation and the parents provided input related to the major challenges that they faced in relation to the diagram of care. They also provided guidance on how to talk with parents about their experiences with a child with a life-threatening condition in a sensitive and respectful way.

The second advisory group meeting discussed the list of themes that resulted from the parents' stories from the first advisory group to give the parents a chance to examine and revise the themes. The major focus of the second meeting was the TRICARE benefit summary (Appendix 3). Parents were asked how they were able to access the services provided by TRICARE, what barriers they have faced in getting the care that their child needed, and what methods or strategies helped improve access to care. Combining these issues with proposed discussion points from the first meeting, the parents crafted questions for use with the parent focus groups and interviews that would help achieve a thorough understanding of the needs of the families while also being sensitive to the difficult issues being discussed.

Quality of Life Survey

The goal of the third advisory group meeting was to introduce and adapt the quality of life survey for use in this project. (Appendix 4) The survey was originally written for children with developmental delays and was designed to measure the quality of life of caregivers. Adaptations were necessary in order to focus this survey on a population of children with life-threatening conditions and their families. The survey was designed to function both as a guide for data collection during the interviews and focus groups as well as a quality measure for any future demonstration program. During the third advisory group meeting, parents were asked to provide comments and suggestions on how to adapt the survey. After being introduced to the concept of quality of life, parents reviewed the questions of the survey and helped to develop and modify categories to describe the major topics. The parents identified missing concepts, agreed on the major thematic categories of the questions, and identified questions for exclusion.

In addition to the advisory group input on the survey tool, a graduate student conducted a statistical analysis on the survey using data previously collected from a study on early intervention programs. The main finding from the analysis was that the survey had strong internal consistency and served as a robust measure of quality of life. The analysis indicated two major themes related to the role of the parents and the access to care. The work also determined that six of the questions were redundant or produced inconsistent results, indicating that minor revisions were necessary. Using the recommendations from both the advisory groups and the work done by the graduate student, the quality of life survey will be adapted for use with families in this project.

Needs Assessment: Parent Groups

Relevant objective in SOW: Objective 1 (FY03 proposal), Objective 1 (FY04 proposal)

The recruitment of parents and the scheduling of interviews are on-going. The group of currently enrolled parents has representation from all major military service branches, both officer and enlisted, and from various racial and ethnic backgrounds. The children of the enrolled parents ranged in age from 4 to 17 years and have either died or were actively involved in treatment for their disease. The diagnoses cover a wide variety of disease trajectories encompassing all four Himelstein categories. The description of the parent groups will be discussed with the research team to determine whether they reflect sufficient diversity.

Analysis of the transcripts from the interviews has yielded a preliminary list of themes which has begun to identify the needs of families and the difficulties they face. (Appendix 5) The following major categories of themes are based on a qualitative analysis of 5 transcripts (2 focus groups and three interviews representing 8 parents):

• Access to existing health care and other services	• Seeking meaning
• Relationships and communication with health care providers	• Parents' roles
• Emotional toll on child, parents, and family	• Palliative care
• Military issues	• Mental health
• Need care for survivors	• Care coordination
• Advocacy	• Recommendations for the system
• Decision-making	• Respite care

Needs Assessment: Health Care Providers

Relevant objective in SOW: Objective 2 (FY03proposal), Objective 1 (FY04 proposal)

Interviews have been conducted with eleven health care providers from various disciplines and departments. The participants included pediatricians, pediatric subspecialists, neonatology fellows, an internal medicine physician, clinical nurse specialists, social workers, and palliative care experts. The health care providers represented two major medical facilities in the national

capital area. Two of the providers had significant experience serving overseas at a military treatment facility in Europe. Analysis of the transcripts and development of a list of themes is in progress. One group not represented is the TRICARE contractor providers. The array of representation from various healthcare provider groups will be discussed with the research team to determine which additional health care provider groups or professions need to be included for proper diversity.

Analysis of the Military Health System Benefit

Relevant objective in SOW: Objective 3 (FY 03 proposal)

The actual health care benefits likely to be used by a military family and child with a life-threatening illness were analyzed with specific citation, description, definitions and comments. This analysis was included in the Annual Progress Report for 2004. (Appendix 6) The components of a CHI PACC® program were listed from the literature and compared to the benefits available through TRICARE. The major categories of services noted to be "missing" from the MHS benefit were: care coordination as a separate, proactive service; respite care and home health care, both having some administrative flexibility regarding the skill level of the individual providing the services; and bereavement counseling after the child's death, that was not necessarily linked to traditional mental health services. In addition, the approach to disease management for these children should require the development of a written plan of care with parental input that integrates palliative care concurrently with disease-directed care and that is family centered and culturally sensitive. These philosophical principles are emerging world wide as the standard of care for children with life threatening illnesses.

Based on this analysis, a draft program rules document for a palliative care program benefit was written (Appendix 7). This draft document outlined the complete elements of an ideal integrated palliative care program that would supplement the existing benefit. Some of the benefits in the proposed rule, such as expressive therapies and the reimbursement of the parent who stays home from work to provide nursing/custodial care, are not standards and services from the CHI PACC® proposed standards, but are services that have been integrated into palliative care by other nationally recognized pediatric palliative care programs. These services would be difficult to provide under the current benefit because of the mandate that TRICARE dollars be used to pay only for medically necessary services, delivered by qualified providers.

Analysis of detailed parent interviews and a direct question to the parent advisory group indicated that care coordination is the most vital of the "missing" services. Although the current practice in the MHS is to provide some aspects of case management, much of the coordination is being done either by the primary care physician or by the parents themselves. This practice adds additional burden to the parents in the care of their children, is time consuming, not well organized or comprehensive, and likely emotionally draining and often distracting from the primary roles of the physicians and the parents.

Members of the team held meetings with the senior representatives in the TRICARE Management Activity (TMA) to present preliminary thoughts and possible recommendations and to discuss TRICARE issues as related to policy and strategy for this project. They discussed the mechanism of the demonstration authority and the requirements for using this process to

implement the project under TRICARE. Demonstration projects allow for some flexibility of the benefit with appropriate outcome measures to assess effectiveness, much like the intent of the Medicaid waiver process. Although support for a full demonstration project was not forthcoming, what emerged from these discussions was an interest in care coordination as the primary focus of any recommendations. The TMA officials expressed support for improving care coordination and offered to provide a cost analysis of care coordination, along with the additional services of respite care, home health care with provider flexibility and bereavement counseling, done by their consultants. This analysis is currently underway.

Population and Eligibility Criteria

Relevant objective in SOW: Objective 4 (FY 03 proposal), Objective 2 (FY 04 proposal)

Attempts to obtain population estimates on the potentially eligible children among military beneficiaries using the avenues for data collection and analysis previously described in the Annual Progress Report from 2004 were not successful. Data available through this particular consultant included only TRICARE prime beneficiaries, which would skew the population estimates.

Review of an approach drawing on the International Classification of Diseases, Revision 9 (ICD-9) codes and severity indices used by the states of Kentucky and Utah to determine eligibility for their CHI PACC® Medicaid waiver applications showed a very wide variation in the severity of diseases that could be included if one searched on the ICD-9 codes alone. Many of those diagnoses counted would not be appropriate for a palliative care program. Furthermore, the indices of severity necessary to isolate those patients with life-threatening conditions from those with just chronic conditions are not easily searchable in the MHS databases.

The research team searched the literature and queried known programs for how prevalence rates and estimates of numbers were calculated for children in the U.S. as a whole, within particular health systems in the U.S., and in other health system settings in other countries. They found three approaches to estimating numbers of children with life-threatening conditions.

1. Count deaths over a defined period of time in the Medicaid population, e.g. Kentucky CHI-PACC® program. This method only works for programs that determine eligibility based on proximity to death and leads to an underestimate of the population.
2. Figure current costs, then define eligible children and design a program to fit within this cost, e.g. Utah's earlier efforts and the current 1915c waivers in Medicaid. This method works for programs that must show cost neutrality and leads to limitations of entitlement and waiting lists for the program. Because the MHS is an entitlement program, all eligible children must receive the benefit based on need and cannot be excluded by cost considerations.
3. Start with a definition of children with life-threatening conditions and then count children that fit that definition. Approaches to defining eligibility include using a narrow definition and then counting from health records, e.g. the United Kingdom (UK) data or employing a broad definition and counting all children with health care special needs (CSHCN) based diagnosis (ICD-9 codes); e.g. the method used by the National Association of Children's Hospitals and Related Institutions (NACHRI).

The approach used by the United Kingdom seemed most applicable to the military population. The U.K. definition of children with life threatening illness was based on a non-categorical description first proposed by the Association for Care of Children with Life-Threatening or Terminal Illnesses and Their Families (ACT) (Royal College of Pediatrics, Great Britain), and later endorsed by Himelstein in his 2004 paper[i,ii]. This non-categorical approach to defining life threatening illnesses outlines the various pathways or disease-related trajectories towards death or the possibility of death over the natural course of the illness, rather than listing types of diseases by using specific ICD-9 diagnostic codes. This definition seemed to best describe our intended population as it enabled the inclusion of children, who were more likely to benefit from palliative care, based more on the severity of the illness rather than a diagnosis alone. Use of this definition could also better demonstrate different health care usage patterns and costs among the four different descriptions (perhaps connoting different management strategies); was manageable for a database search; and could guide policy decisions in program development. These definitions are: Group A. Progressive conditions in which treatment is exclusively palliative from point of diagnosis; Group B. Conditions requiring long periods of intensive treatment aimed at prolonging life and improving the quality of life, but ultimately have no cure; Group C. Conditions for which curative treatment is possible but may fail; Group D. Conditions with severe, non-progressive disability causing extreme vulnerability to health complications which themselves might lead to death.

Using this definition, data from different districts in the United Kingdom indicated that the prevalence of life-threatening conditions ranged between 1.0:1000 to 1.72:1000.[iii,iv,v]. The U.K. method counted actual records to determine prevalence and the counts included children living with life threatening illness with the goal of developing a program for these children. The differences in the rates could be due, in part, to differences in defining the population and/or the method of determining the population. The U.K method most closely approximated the requirements for estimating the population within the MHS. These non-categorical definitions most suited the approach preferred by this team. By applying this prevalence rate of between 1.0:1000 and 1.72:1000 to the MHS, the approximate number of children in the military with life-threatening conditions is estimated to be between 2,408 and 4,141 children out of a total of 2,641,554 pediatric beneficiaries.

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[i] Association for Children with Life-threatening or Terminal Conditions and their Families, Royal College of Pediatrics and Child Health. *A Guide to the Development of Children's Palliative Care Services.* 1997.

[ii] Himelstein B, Hilden J, Boldt A, et al. Medical progress: Pediatric Palliative Care. N Eng J Med 2004; 350:1752-62.

[iii] Association for Children with Life-threatening or Terminal Conditions and their Families, Royal College of Pediatrics and Child Health. *A Guide to the Development of Children's Palliative Care Services. Second Edition.* 2003.

[iv] Lenton SW, Stallard P, Lewis M, Mastroyannopoulou K, (2001). Prevalence and morbidity associated with nonmalignant life threatening conditions in childhood. Child Care, Health and Development, 27 (5): 389-398.

[v] Maguire H (2000). Assessment of need of life-limited children in Northern Ireland. Northern Ireland Hospice Children's Service.

This estimate for children in the MHS with life threatening conditions was compared with a population count obtained from an actual search of MHS databases. Since the cost and time for counting actual records was prohibitive, representative diagnoses and corresponding ICD-9 codes for each disease trajectory were selected by the team for use in the database search. Diagnostic codes were chosen by reviewing lists from state Medicaid waiver programs, by reviewing diagnostic lists from military programs for special needs, such as Program for Persons with Disabilities and were based on clinical experience, with the realization that using only these codes in the search would produce an underestimate of the numbers of children with each type of disease course. The diagnoses and corresponding ICD-9 codes for the four groups are shown in the following chart:

ICD-9 codes for conditions

Our designation for this condition	Description	Examples	ICD-9 codes
A	Progressive	SMA, trisomy 13,18, severe asphyxia	335.0, 335.10, 335.11, 758.1, 758.1, 758.3, 768.0, 768.1, 768.2, 768.5
B	Require long periods of intensive care aimed at improving quality of life	Cystic fibrosis, muscular dystrophy	277.00, 277.01, 359.1
C	Curative treatment is possible but may fail	Any childhood leukemia or cancer	191.x, 204.xx, 206.xx, 207.xx, 208.xx, 209.xx
D	Severe, nonprogressive, extreme vulnerabilty	Spastic quadriplegia, tracheostomy	343.1, V55.0

The database searched was the MHS Management Analysis and Reporting Tool (M2). M2 is a powerful tool used to obtain summary and detailed views of population, clinical, and financial data from all MHS regions. M2 includes Military Treatment Facility (MTF) and commercial network claims data integrated with eligibility and enrollment data. This integrated data enhances support to healthcare managers across the MHS. M2 allows users to perform trend analyses, conduct patient and provider profiling studies, and conduct business case analyses to maximize health plan efficiency. Within M2 are the MTF Standard Inpatient Data Record (SIDR), the Standard Ambulatory Data Record (SADR), and the purchased care information known as the Health Care Service Record (HCSR). The search encompassed patient data for a two year span (October 1, 2000 – September 30, 2002) for children in the military health system 0-24 years who were alive during any part of the study period. The data indicated that a total of 3976 children with life threatening illnesses are in the MHS for a prevalence rate of 0.15%. This number falls within the calculated range of eligible children in the MHS based on the U.K.

prevalence rates (0.10% - 0.172% or between 2,408 and 4,141 children). The death rate data may be an underestimate, as the most accurate reporting of deaths occurs only when a child dies in a health care facility.

Counts of Children with LTCs in the MHS

Our designation for this condition	Description	Numbers of Children Alive at End of Study Period	Numbers of Children Who Died During Study Period
A	Progressive	728	25
B	Require long periods of intensive care aimed at improving quality of life	964	8
C	Curative treatment is possible but may fail	1239	54
D	Severe, nonprogressive, extreme vulnerabilty	940	18
Total		3871	105

Resources Available to Military Families

Relevant objective in SOW: Objectives 3 and 5 (FY 03 proposal)

The Coordinating Center (TCC) was primarily responsible for conducting a literature review on resources; developing a resource assessment tool and researching what resources are typically available to families in a community. This aspect of the study was designed to answer the following questions: What types of supports are available to children with life threatening conditions and their families? Where is information about community resources located? What is the process for accessing community resource information? What are some of the barriers for families in identifying and finding resource information? What strategies can be incorporated in a new model design to optimize access to information about community resources? The attached document is the completed analysis to date. (Appendix 8) Only summary conclusions and recommendations will be provided in this portion of the annual progress report.

Based on an extensive review of potential resources for children with life threatening conditions, there appear to be numerous possible sources of support available to military families living in the National Capital Area (NCA). Many of the resources are national in scope or government related and, therefore, available in other areas of the country, or otherwise commonly available in most communities. Hence, the information gleaned from this study can be generalized to communities other than the NCA. However, much of the problem seems to lie in the barriers to

accessing services rather than in their lack of availability. Types of barriers include limits set by specific diagnostic or financial eligibility criteria, geographic limitations, lack of knowledge or skills with the pediatric population, prohibitive costs, waiting lists or enrollment caps. Further analysis of resources compared to the needs assessment could reveal additional gaps in existing resources for children and families in the military. These gaps will be further evaluated and ultimately incorporated into a new model design as other components of this project are completed.

A Resource Profile Chart (Appendix 8, Attachment G) has been developed to identify types of resources relevant to children with life threatening conditions and the general location of these resources. It is important to note that most organizations and programs that house resources for families have specific factors and guidelines that determine a child's and family's eligibility for the specific service. The details of these factors are far too many to include in the chart. The purpose of the chart is to be a general reference to identify some possible options and guidance to families seeking resources. The Resource Overview Analysis chart (Appendix 8, Attachment H**)** is an attempt to answer the original questions posed and provides an overview of the general conclusions relating to resources and the issues families might face in attempting to access services at the federal, state, and local levels as well as those resources within the military community.

Results of this work have led to the following preliminary recommendations for consideration in the new model design:

Education

- Educate families and providers regarding the types of resources that exist and where they may be located.
- Educate families of children with life threatening conditions to utilize existing military services such as Military One Source and Military Home Front.
- Educate Military One Source staff on the variety of specific resources that exist for families who have children with life threatening conditions to enhance dissemination of information to families who are seeking community support.

Coordination and Facilitation

- Consider care coordination as a means to assist families in accessing existing resources both in the military and private sectors.
- Develop linkages for families with Military One Source to optimize an information and referral role they are currently contracted to deliver to active military personnel.
- Encourage the collaboration of existing community programs that provide various types of coordination such as public libraries, Infant and Toddler Programs, school programs, Military One Source, etc. that already exist within the military or civilian world.

System Design

- Design information systems to support the dissemination and access to resource information focused on supporting children with life threatening conditions.
- Encourage family networking through such chat forums as Military and Specialized Training of Military Parents (STOMP). This type of networking provides families with experience and information on strategies to problem solve system barriers. A

parent may get information to assist them in navigating systems and accessing services to support their children's needs.

- Incorporate quality indicators and metrics to measure usage and access to all possible resources that support families. By optimizing the use of resources within the military system, such as TRICARE and Military One Source, and supplementing these with resources that families can access outside of the military system, a full spectrum of services appears to be available to support families. This type of quality review may assist the developing model to better identify potential areas for process improvement, especially related to the process for accessing the resource, and help to address some of the areas of vulnerability.

Resource Database and Website Development

Relevant objective in SOW: Objective 7 (FY 03 proposal), Objectives 3 and 4 (FY 04 proposal)

The Coordinating Center initially proposed to develop a web-based database. The purpose of this database was to house the resource data identified during this review of resources. Since the ultimate goal of the project was to design a model that could be used across the MHS, the team felt that there was a need to present the resource information from a broader perspective, one that could be applied to any community. Therefore, the team determined that the specific data that would be collected and included in a database for the NCA would not be useful in a broad application of model design. In addition, the resource review findings included an extensive list of existing databases that are currently accessible on the Internet for families who have children with special healthcare needs. The project team requested a more global presentation of resources that currently exist based on the evolving nature of the project, the changing needs of the project team, and the existence of other resource databases. To meet that request, The Coordinating Center used the data obtained in the resource review to develop several charts to assist the project team in identifying trends, challenges and barriers related to community resources. (See documents presented under "Resources available to military families".) In addition, a Resource Profile Chart (Appendix 8, Attachment G) was developed and populated to list potential services and resources that are applicable to children with life threatening conditions and global programs that may provide access to such services. The Resource Profile Chart can be applied to any area of the United States where a model program may be developed.

Models of Care Coordination

Relevant objective in SOW: Objective 8 (FY 03 proposal)

Care coordination is emerging as a major focus of this project and most likely the key recommendation for a pediatric palliative care model. The Coordinating Center (TCC) has provided to the team background on case management as a service and a discussion on the various models of case management that are utilized in the general medical community. TCC has also outlined the broader services encompassed by care coordination and how this service might apply to military families of children with life-threatening illnesses.

Case management is defined by the Case Management Society of America (CMSA) as "a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality, cost-effective outcomes". (Definition obtained from CMSA Standards of Practice, 2002) Third party payers and managed care programs often use the term "case management", others prefer the term "care coordination". Typically case management may include activities such as disease management, benefits management and utilization review, while "care coordination" occurs when an individualized plan of care is implemented by a variety of service providers. (Committee on Children with Disabilities, Pediatrics, 1999) Care coordination is often the preferred term used in context of family centeredness as parents play such an integral role in the management of their child's care. For the purposes of this project, case management will be presented within a conceptual framework best described as child and family centered and the term care coordination seems to better describe this service for children with life threatening conditions.

Care coordination is a service commonly found in some of the state level programs discussed in this report, particularly those serving children with special health care needs. For example, care coordination is a component service provided with early intervention programs, developmental disability programs as well as the community based waivers for children. Care coordination is also identified by Children's Hospice International as a key component of the CHI PACC® model.

According to the Massachusetts Consortium for Children with Special Health Care Needs, "care coordination is a central, ongoing component of an effective system of care for children and youth with special health care needs and their families." (Care Coordination: Definition and Principles, prepared by the Care Coordination Work Group, Oct 2005) This same concept is widely accepted by the American Academy of Pediatrics (AAP) based on their support of the medical home concept. As defined by the AAP, a medical home is an approach to comprehensive primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. The AAP Committee on Children with Disabilities recently concluded that care coordination is an integral component to the efficient management of the multiple complex issues related to caring for children with special health care needs to result in optimal outcomes for children and their families. In addition, based on the needs of children across multiple health and human service systems, care coordination is a process that links children and families to services and resources. The care coordination of children with complex health care needs is often not provided by the pediatrician based on lack of time and staff. (Gupta, O'Connor and Quezada-Gomez, Pediatrics 2004)

Care coordination activities may offer benefits to families and to providers. Some specific activities that care coordination can provide in relationship to accessing resources may include but are not limited to the following:

- Assess the individual needs of the child and family
- Develop an individualized plan of care for the child incorporating the multidisciplinary team
- Understand the range of available community resources and public benefits

- Identify, locate and monitor community resources to assist the child and family
- Facilitate access to health and other services that support the needs of the child and family
- Optimize resources that are available to the child, while avoiding duplicative or unnecessary services and costs
- Facilitate effective communication between families and providers
- Assist the family to become more effective advocates for their child's needs

Work is still ongoing to determine which model of care coordination to use, what the requirements are and how to implement this model within the MHS.

Gap Analysis

Relevant objective in SOW: Objective 9 (FY 03 proposal)

Data from the research on the family needs assessment and the development of themes related to family needs is preliminary. Based on the findings to date, an initial comparison between needs and resources was made. In many areas, care coordination might be the service that can fill the gap for families' needs and their ability to access appropriate resources. The following chart provides a very preliminary attempt at addressing the gaps in resources. The gray areas of the chart represent topic categories identified as preliminary themes from focus group work. The themes are then further detailed in the far left column of the table. These details were cross referenced to resources that were found to exist in the general community setting that may address the challenges listed.

Access to healthcare and other services		
Challenge Identified in Focus Work Group	**Possible Existing Resource**	**Comments**
Services are hard to get	• Care coordination	Identifying and locating possible resources. Facilitate application to resources. Assist with collecting documentation to obtain the resources.
Families dealing with conflict related to school	• Care coordination • Mediation	Requires trouble shooting of issue and identification of possible solutions. Negotiation may be necessary to resolve the conflict.
Families dealing with conflict with TRICARE	• Care coordination	This may be a benefit issue, communication issue or system issue.
Fighting for everything	• Care coordination	This may be a benefit issue, communication issue or system issue. Managing expectations is important to avoid family feeling defeated.
Inflexible	• Care coordination	This may be a benefit issue, communication issue or system issue. Additional options may need to identified and considered.

MA waivers are limited	• Care coordination	Pursue other programs or resources.
MHS is inconsistent - need people who know system	• Care coordination	Managing expectations is essential - could be asking the wrong person or department.
Continuity of care	• Care coordination	Managing expectations is essential.
Lack of time with physicians	• Care coordination	May be a system issue or communication issue.
Services are inconvenient (long wait times)	• Care coordination	May be a system issue or a specific provider issue.
Difficult relationships and communication with providers	• Care coordination • Counseling	May require education for parents related strategies for dealing with difficult personalities.
Emotional toll	• Counseling	
Spousal/ Partner relationships	• Counseling • Legal resources	

Employer Issues		
	Possible Existing Resource	**Comments**
Assistance with military environment	• Care coordination could assist families in presenting the information to the employer and advocating for support • EFMP would also play a role in this area	These employer issues will require resources within the military system to resolve.
Education to commanders who are dealing with these types of personnel issues		
Conflict resolution resource related to dealing with military requirements		
Help with parents who are stationed abroad		

Survivor Issues		
	Possible Existing Resource	**Comments**
Care for children who survive illness, such as latent effects of CA treatment or how to talk to adolescents regarding fertility issues as a result of treatment.	Specialty counseling such as genetic counseling	

Education Plan

Relevant objective in SOW: Objective 2 (FY 03 proposal), Objectives 1 and 5 (FY 04 proposal)

As this project has evolved, the scope of the education plan has broadened to include more than the training of direct care providers and the education of families on the program benefits. The approach to the education plan will identify all appropriate stake holders in a pediatric palliative care program and the "education" required for the successful implementation of a proposed plan. The identification of the various stake holders will emerge from work done by the parent and provider needs assessment focus groups and interviews, and from the development of the components of the program model. The plan will outline the requirements for education,

methods for providing the education, to include traditional education curricula for direct care providers, web-based information and educational tools especially as related to the managed care support contractors, and marketing strategies for the providers and families, as well as the costs associated with developing and implementing the education plans. No specific work has been done in this area to date.

Standards of Care, Outcome Measures and Quality Assurance

Relevant objective in SOW: Objectives 6 and 10 (FY 03 proposal)

The existing document, the CHI PACC ® Standards and Guidelines of Care, served as the basis for preliminary work on the development of standards and measurable outcomes. There are four basic standards for delivering pediatric palliative care: comprehensive written plan of care by an interdisciplinary team, a plan of care that integrates palliative care with disease-directed care, care from the point of diagnosis with an identified care coordinator, and adequate and flexible funding. For each of these standards, the team identified the key required components and developed a definition for each that is tailored for the military system. (Appendix 9) Work in this area will continue in the next year.

KEY RESEARCH ACCOMPLISHMENTS

- The USUHS research team has begun to develop themes from their interviews of parents and providers. An initial comparison with issues related to resource availability points to care coordination as a key component of any program model.
- Based on an extensive review of potential resources for children with life threatening conditions, there appears to be an abundance of possible sources of support available to military families. Barriers to availability may be related to the lack of awareness of the resource, accessibility issues, eligibility requirements, quality of the service provided, limited knowledge of how services could be applicable, or financial restrictions. Many of these barriers and challenges could be alleviated or obviated by consistent support through care coordination.
- An analysis of the military healthcare benefit revealed that certain services important to the provision of pediatric palliative care were either not included in the benefit or were not available in a way that would best help this population. These services include care coordination as a separate, proactive service; respite care and home health care, both having some administrative flexibility regarding the skill level of the individual providing the services; and bereavement counseling after the child's death that was not necessarily linked to traditional mental health services.
- Using methodology adapted from work done in the United Kingdom and a non-categorical approach to defining the population, reasonable estimates of the numbers of children with life threatening illness were obtained for a two year period from MHS and purchased care databases. The numbers were consistent with more global estimates derived by applying the percentage of children with life threatening illness obtained from the literature to the total number of eligible children in the MHS M2 database.

- Discussions with officials from TMA have led to preliminary interest and support for a focus on care coordination and recommendations on how to improve this service in the MHS.

REPORTABLE OUTCOMES

None at this time.

CONCLUSIONS

- The work for this last year will focus on the recommendations for a program model, to include implementation strategies and associated costs.
- The team will pursue any and all avenues for additional funding to support a demonstration or pilot of the program model.
- Two major areas of work, (1) education, training and marketing (Objective 6), and (2) outcome measures and quality assurance (Objective 10), have yet to be completed. Henry M. Jackson Foundation subcontractor, Children's Hospice International (CHI), has been responsible for taking the lead in these two areas since December 29, 2003, the beginning of the performance period of the subcontract. CHI's cost reimbursement subcontract expired December 28, 2005. Over the final six months of the contract, a concerted effort was made to get CHI to focus on these objectives, but with no tangible results. CHI has not made sufficient progress toward completion of these two objectives in the past two years to justify an extension or renewal of their subcontract. There is funding remaining on the subcontract (the exact amount to be determined when the subcontract is formally closed-out). Plans for the redirection of these funds to another subcontractor to complete these objectives will be developed in the near future. Over the course of the subcontract period of performance the following meetings, as noted below, provided CHI representatives updates on the course of the project to include team reporting of goals and tasks as assigned in statement of work.

- 12/28/03: Initial date of contract award for entire project from CDMRP to HJF.
- 11/4/04: Meeting with Ann Armstrong-Daily (CHI), David Lee (CHI) Cheryl Naulty (PI), Deona Howard (HJF) and Maxine Lippman (HJF, contracting) to sign subcontract.
    - Objectives included in SOW
    - Preliminary work on other objectives in CHI SOW done prior to that time.
- 11/17/04: Team meeting with Cheryl Naulty (PI), Deb Wills (WRAMC), Karen-Ann Lichtenstein(TCC), Julie Lausch (TCC), Carol Marsiglia (TCC, Jeanette Osbourne (CHI consultant), Pamela Cunningham(TMA), Virginia Randall (USUHS), David Lee (CHI), Jan Hanson (USUHS), Mel Bellin (USUHS) and Deona Howard (HJF)
    - Overview of total project; discussion on objectives 6 & 10.
- 12/17/04: CHI submission of annual report, written by David Lee (CHI)
    - Objective 6: reference to contract with Educational Development Center (EDC) re: plans to use their curriculum
    - Objective 10: Preliminary exploration of existing evaluation tolls or possible use of a consultant.

- 3/25/05: Meeting with Ann Armstrong-Daily (CHI), Jane Koppleman (CHI), Brian Greffe, MD (CHI consultant), Cheryl Naulty (PI), Deona Howard (HJF)
    - Introduction of Jane Koppleman, replacing David Lee.
    - Brief on project, changes in direction of several objectives, including 6 & 10.
    - Asked for rebudget and clarification of roles of new CHI staff and consultant.
- 5/4/05: Team meeting, including Jane Koppleman (CHI), Ann Armstrong-Daily (CHI) Cheryl Naulty (PI), Jan Hanson (USUHS), Virginia Randall (USUHS), Deona Howard (HJF), and Mildred Solomon, David Browning (EDC representatives/CHI consultants) to discuss role of EDC in project.
    - Changed directions from use of a specific palliative care curriculum (IPPC developed by EDC) to broader educational goals as well as possible EDC involvement in development of outcome measures.
- 6/15/05: Meeting at CHI with Jane Koppleman (CHI), Cheryl Naulty (PI) and Deona Howard (HJF) for help CHI frame their subcontract with EDC re: objectives 6 & 10.
- 7/13/05: Team meeting, including Jane Koppleman (CHI), Ann Armstrong-Daily (CHI), and Brian Greffe (CHI consultant) plus Mark Edelstein, Anna Romer, Mildred Solomon (EDC representatives), Cheryl Naulty (PI) Carol Marsiglia (TCC), Deb Wills (WRAMC), Jan Hanson (USUHS), Deona Howard (HJF) Entire meeting devoted to discussions on objectives 6 & 10.
- 7/22/05: HJF contract office reviewed CHI/EDC contract language at CHI's request.
- 8/24/05: Meeting at CHI with Jane Koppleman (CHI), Cheryl Naulty (PI), and Deona Howard (HJF) to reevaluate CHI SOW; purpose: to clarify for CHI tasks completed and tasks remaining, including work for objectives 6 & 10.
- 9/7/05: Team meeting with Cheryl Naulty (PI) Carol Marsiglia (TCC), Karen-All Lichtenstein (TCC), Jason Cervenka (USUHS), Jane Koppelman (CHI), Jan Hanson (USUHS), Pam Cunningham (TMA), and Deona Howard (HJF)
    - Reviewed all objectives for entire team so everyone understood what work was completed; what work remained; how certain objectives had changed or were not longer valid based on findings to date.
    - CHI assigned task: schedule brainstorming session with EDC regarding objectives 6 & 10.
- 9/14/05: Team meeting with Cheryl Naulty (PI), Carol Marsiglia (TCC), Karen-Ann Lichtenstein (TCC), Jason Cervenka (USUHS), Jane Koppelman (CHI), Brian Greffe (CHI consultant), Jan Hanson (USUHS), Marc Edelstein (EDC representative/CHI consultant), Anna Romer (EDC representative/CHI consultant), Deona Howard (HJF)
- CHI assigned tasks
    - Send out notice for planned education brain storming session with EDC
    - Send out notice for planned outcome measures/quality assurance brainstorming session with EDC.
- 9/21/05: Meeting at CHI with Jane Koppleman (CHI), Deona Howard (HJF), Cheryl Naulty (PI) on revised SOW
- 9/26/05: Received CHI signed SOW, which indicated completed and outstanding objectives, including 6 & 10.
- 10/12/05: Team meeting with Cheryl Naulty (PI) Carol Marsiglia (TCC), Karen-Ann Lichtenstein (TCC), Jan Hanson (USUHS), Jane Koppleman (CHI), Brian Greffe (CHI consultant), and Deona Howard (HJF)

    - CHI presented proposed evaluation tool
    - CHI task: to incorporate input from entire team and continue to develop tool in conjunction with EDC contractors.
- 11/23/05: Meeting at HJF with Jane Koppleman (CHI), Ann Armstrong-Daily (CHI), Marina Maratos (HJF), Gary Ashton (HJF), Maxine Lippman (HJF), Deona Howard (HJF), Cheryl Naulty (PI)
    - Purpose: to review status of CHI deliverables.

APPENDIX 1

IRB Status

USUHS

- Amendment 6, which modified the protocol and consent forms to include changes requested by WRAMC, approved 4/11/05.
- Amendment 7, which modified the parent consent form approved 5/10/05.
- Amendment 8, which added Wright Patterson to replace Keesler Air Force Base as a study site submitted 10/19/05.
- Annual review and continuing approval application approved on 12/1/05.
- Second level reviews completed for all approved site locations.
- Current Status: Approved until 11/30/2006.

WRAMC

- Signed MOA received on 5/9/2005.
- Revised application submitted on 5/9/2005.
- Worked through detailed revision of CRADA.
- Protocol approved 6/3/2005.
- Annual review approved 10/12/05.
- Self audit checklist submitted 12/21/05.
- Current Status: Approved until 6/3/06.

NNMC

- Revised applications submitted on 5/24/05 and 6/10/05.
- Signed MOA received on 6/6/05.
- Protocol approved 6/17/05.
- Current Status: Approved until 6/17/2006.

Malcolm Grow

- Signed MOA received 3/31/05.
- Annual report approved 7/11/05.
- Current Status: Approved until 7/11/06.

Madigan

- Protocol application submitted 9/9/05.
- Revised consent forms submitted 12/14/05.
- Current Status: Currently in review at Madigan IRB.

Keesler Air Force Base

- Protocol application submitted 5/3/05.
- Signed MOA received 6/24/05.
- Protocol approved.
- Current Status: Keesler removed from study due to Hurricane Katrina.

Wright-Patterson

- Protocol application submitted 10/13/05.

- Signed MOA received 10/13/05.
- Current Status: Coordinating with site PI to respond to IRB comments.

San Diego

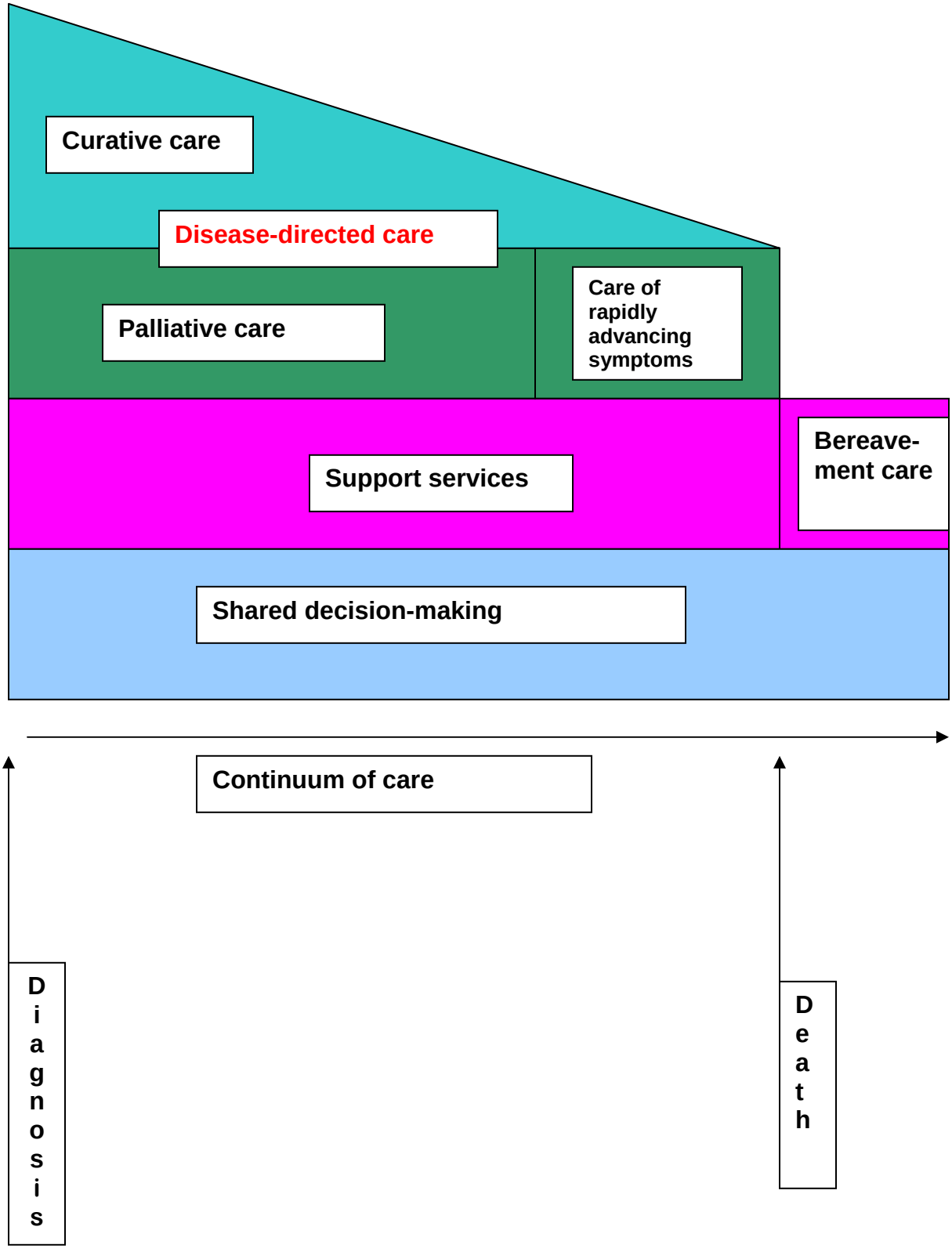
- Signed MOA received 5/19/05.
- Protocol application submitted to IRB 8/3/05.
- Current Status: Awaiting scientific review from Chief of Pediatrics at San Diego for the past three months before complete IRB review can take place.

Ft. Leavenworth

- Application documentation received.
- Current Status: Application being prepared for submission.

APPENDIX 2

Tentative Schematic Diagram of Care



APPENDIX 3

MCARE – Summary of the TRICARE Benefit and the Military Health System

If your child gets sick

- All medically necessary care is provided through MHS.

1. If active duty:

Care at Military Treatment Facilities	All or mostly covered
Outpatient Care	TRICARE Prime – co-pays & cost-shares
	TRICARE Extra – co-pays & cost-shares 15%
	TRICARE Standard – co-pays & cost-shares 20%

2. If retired:

Care at Military Treatment Facilities	All or mostly covered
Outpatient Care	TRICARE Prime – co-pays & cost-shares $460 annual fee per family
	TRICARE Extra – co-pays & cost-shares 20%
	TRICARE Standard – co-pays & cost-shares 25%

3. If you have supplemental insurance – co-pays and cost-shares are covered.

If your child has a long-term need for home health care and has a qualifying condition (mental retardation, a serious physical disability, an extraordinary physical or psychological condition that renders the child home-bound, or receives early intervention services under IDEA,) the child may be eligible for home health care, respite care, and therapy services delivered under a written plan of care.

1. If active duty:

ECHO/EHHC Provides*: ECHO/EHHC requires enrollment in the EFMP	1. Up to $2500 per month of services under the plan of care, after a small co-pay.
	2. EHHC – home health care not limited to part time or intermittent care
	3. EHHC – respite care up to 8 hours per day, 5 days per week

*ECHO/EHHC replaces PFPWD. It is not implemented yet, but the regulation is signed

2. If retired – not eligible for ECHO/EHHC – can pursue Medicaid if
   a) Meet income restrictions
   b) Apply for waiver

Medically Necessary Care includes:	
1. Outpatient doctor visits	6. Limited in-home skilled nursing
2. Inpatient care	7. Limited occupational therapy, physical therapy, speech therapy
3. Medical procedures	8. Diagnostic evaluations and procedures
4. Durable medical equipment	9. Transportation if medical care is needed during the transport
5. Medications and pharmacy supplies	10. Preventive health care

APPENDIX 4

Quality of Life of Caregivers of Children with Special Needs Survey
(Randall and Hanson)

Date : Interviewer : No : edited for mCARE 5-28-04

Quality-of-Life of Caregivers of Children with Special Needs

For each question, fill in the circle that best describes your answer. Use circles 2 or 4 if your answer falls between 1,3 or 5. There are no "correct" answers, everyone experiences the caregiving challenges differently.

1. Can you help your child gain living skills?

○ 1. I have a very difficult time helping my child learn living skills.
○ 2.
○ 3. About half the time, I can help my child learn living skills, but sometimes it is a struggle.
○ 4.
○ 5. I can easily help my child learn living skills.

2. Are you able to enjoy your child?

○ 1. I can't find anything that my child and I enjoy doing together and I don't know where to start.
○ 2
○ 3. I can sometimes find enjoyable things to do with my child.
○ 4
○ 5. I am usually able to find or create fun experiences for me and my child.

3. Does your child have all the equipment, therapy, and special education he/she needs?

○ 1.I have not been able to get the appropriate education, therapy, and/or equipment for my child.
○ 2.
○ 3. I have found some of the education, therapy, and/or equipment that my child needs.
○ 4.
○ 5. I have found all the resources necessary to enchance my child's medical care and education.

4. Are you able to be an advocate?

○ 1. I haven't figured out how to be an effective advocate for my own child or for other children.
○ 2.
○ 3. I can advocate for my own child, but I haven't yet found ways to make a difference for others.
○ 4.
○ 5. I have found ways to make life better for my child and others.

5. How has being a parent of a child with special needs changed your life? How have the changes affected you?

○ 1. Being a parent of my child consumes my life. I resent the changes I've had to make in my life.
○ 2.
○ 3. I'm resigned to the changes I've had to make and begun to integrate my child's needs and my own.
○ 4.
○ 5. I'm comfortable with the new priorities in my life.

6. Who makes the health care decisions about your child?

○ 1.I don't know much about my child's condition and I let the experts make the decisions.
○ 2.
○ 3. I've learned some things about my child's condition and I make suggestions to the care providers.
○ 4.
○ 5.I know a lot and share opinions and negotiate decisions with the care providers

7. Do you understand how to get the services your child and family need?

○ 1. I don't know how to get services for my child and I usually give up or get upset.
○ 2.
○ 3.I know how to get services but it involves lying, getting hysterical, or becomeing nasty.
○ 4.
○ 5.I know how to get services and I can usually do it in a positive way.

8. How do you spend your time?

○ 1.The needs of my child are so great I don't get anything else done.
○ 2.
○ 3. Most of the time, I can get some housework and shopping done.
○ 4.
○ 5.I spend time taking care of my child but I also get many other things done.

9. Are you concerned about your child's safety?

○ 1.Safety is a daily concern for me regarding my child.
○ 2.
○ 3.My child is safe at home but I worry about him/her in other places.
○ 4.
○ 5.My child has no safety issues because of his/her special needs.

10. How has having a child with special needs affected your finances?

○ 1.I worry about how to pay the bills and my child doesn't have all the things he/she needs.
○ 2.
○ 3.I can manage to make ends meet but it's a strain.
○ 4.
○ 5.I'm OK financially.

11. Is your housing adequate to meet the needs of your child and family?

○ 1.My child's needs cannot be met in our current housing.
○ 2.
○ 3.I've had to compromise on housing because of my child.
○ 4.
○ 5.I have a safe and affordable house that meets my child's needs.

12. Do your child's health care providers listen to you?

○ 1.My child's health care providers don't seem to care about my feelings.
○ 2.
○ 3.Sometimes they listen but sometimes they are too busy.
○ 4.
○ 5.We have care providers who always listen and believe me.

13. Can you reach your child's health care providers when you need to?

○ 1.I am never able to get the health care provider on the phone in a reasonable period of time.
○ 2.
○ 3.Sometimes I can reach him/her in a reasonable time.
○ 4.
○ 5.I can always talk to him/her in a reasonable time.

14. Do you know who to call for a problem or question about your child's health?

○ 1.I'm not sure of who to call for which problem.
○ 2.
○ 3.I know some physicians to call for some problems.
○ 4.
○ 5.I know exactly who to call for any problem.

15. Do you understand your child's medications?

○ 1.I don't understand anything about my child's medications.
○ 2.
○ 3.I have partial understanding of my child's medications.
○ 4.
○ 5.I have an excellent understanding of any medication my child takes.

16. What happens when you are late for an appointment with your child's doctor?

○ 1.If I'm late for an appointment, I have to reschedule and everyone is rude.
○ 2.
○ 3.If I'm late, we are seen but it is uncomfortable.
○ 4.
○ 5.If I'm late, I know the doctors and nurses understand and will see my child.

17. Are you comfortable with the interview style of your child's doctor?

○ 1.I don't feel comfortable with the questions or the insensitive manner of the doctors.
○ 2.
○ 3.I am somewhat comfortable with my doctor's questions and manner.
○ 4.
○ 5.I am very comfortable with my doctor's questions and manner.

18. Does your child's doctor respond to the developmental and emotional needs of your child?

○ 1.My child's doctor is insensitive to the developmental and emotional needs of my child.
○ 2.
○ 3.My child's doctor sometimes responds to my child's needs.
○ 4.
○ 5.My child's doctor always responds to my child's needs.

19. Do you trust your child's primary care provider?
○ 1.My child does not have a primary care provider or if he/she does, I don't trust them.
○ 2.
○ 3.I have a fair amount of confidence in my child's primary care provider.
○ 4.
○ 5.I trust my child's primary care provider completely.

20. Do you know what to do in an emergency?
○ 1.I am not at all sure what to do in a medical emergency.
○ 2.
○ 3.I have a general idea of what to do in an emergency.
○ 4.
○ 5.I have a written plan for what to do in an emergency.

21. Do you need help coordinating your child's care?
○ 1. I have to do all the care coordination myself and the hassle and complexity are overwhelming.
○ 2.
○ 3.Most of the time I can handle the coordination and paperwork, but I would like some help.
○ 4.
○ 5.I don't need any help with care coordination.

22. Did your child start receiving services as soon as he/she needed to?
○ 1. The diagnosis was made too late for my child's best interests and he/she missed needed services.
○ 2.
○ 3.It took longer than I wanted, but my child didn't miss any important services.
○ 4.
○ 5.From the time I suspected something wrong, to when services started, was very short.

23. Are your child's "well child" needs (immunizations, routine discussions about safety and discipline) being taken care of?
○ 1. The "well child" needs of my child are always overlooked.
○ 2.
○ 3. The "well child" needs of my child are sometimes met.
○ 4.
○ 5. The "well child" needs of my child are always met.

24. Is your child's doctor sensitive to ethnic and cultural diversity?
○ 1.I don't think my child's doctor ever heard of cultural diversity or sensitivity training.
○ 2.
○ 3.My doctor tries to understand different cultural practices.
○ 4.
○ 5.My doctor understands my culture and beliefs and works with me.

25. How are your immediate family members coping?
○ 1. My family members are having a very difficult time coping with my child's condition.
○ 2.
○ 3.My family members can usually cope.
○ 4.
○ 5.My family members are coping very well.

26. Have you begun to plan for your child's future?
○ 1.The issues of my child's future are so difficult for me I can't begin to think about them.
○ 2.
○ 3.I have a good idea of what I need to do to prepare for the future.
○ 4.
○ 5.I've made all the plans that need to be made.

27. Are you getting the sleep you need?
○ 1.Because of my child, I never get enough sleep and am perpetually fatigued.
○ 2.
○ 3.Sleep is only an occasional problem.
○ 4.
○ 5.Sleep is never a problem.

28. What has been the effect on you or your spouse's career of having a child with special needs?
○ 1.One or both parents' careers have definitely been hurt by having a child with special needs.
○ 2.
○ 3.One or both careers may have been hurt.
○ 4.
○ 5.Neither parents' careers have been hurt.

29. Do you have any time to do something just for yourself?
- ○ 1.I devote all my time to my child and have no spare time for myself.
- ○ 2.
- ○ 3.I have some time for myself to do things I like.
- ○ 4.
- ○ 5.I have plenty of time to do things just for myself.

30. Do you get a break from caregiving (respite care)?
- ○ 1.We never get away from the constant demands of caregiving.
- ○ 2.
- ○ 3.We sometimes get away, but not enough.
- ○ 4.
- ○ 5.We have frequent enough breaks from caregiving.

31. Are you able to be hopeful?
- ○ 1.I find no purpose or hope in this unfortunate situation for my child.
- ○ 2.
- ○ 3.Sometimes I can make sense out of what has happened and see some hope.
- ○ 4.
- ○ 5.I have been able to find inner peace about my child's condition.

32. Is grief and sadness a problem for you?
- ○ 1.I feel constant grief and sadness over my child's condition.
- ○ 2.
- ○ 3.I usually feel grief and sadness.
- ○ 4.
- ○ 5.I usually do not feel grief or sadness.

35. Have you been injured in caring for your child? Has your child injured you?
- ○ 1.I, myself, have been seriously injured.
- ○ 2.
- ○ 3.I have been mildly injured.
- ○ 4.
- ○ 5.I have never been injured.

36. Do you have any physical symptoms of stress?
- ○ 1.I have many physical symptoms of stress like headaches, bowel problems, insomnia.
- ○ 2.
- ○ 3.I have a few mild physical symptoms of stress.
- ○ 4.
- ○ 5.I have no effects on my own physical health.

37. How much of a problem is worry for you?
- ○ 1. I constantly worry about my child. There is never a time I do not think about it.
- ○ 2.
- ○ 3. I worry a fair amount but not all the time.
- ○ 4.
- ○ 5.I don't worry.

38. What kind of support do you have?
- ○ 1.I feel isolated and alone. I have no support. I don't know who to ask for help.
- ○ 2.
- ○ 3.I get some support from family and friends, but basically I "go it alone."
- ○ 4.
- ○ 5.My support system of family and friends keeps me going.

39. Have you been able to maintain your religious beliefs?
- ○ 1. Because of my child's condition,I am totally alienated from my previous religious beliefs.
- ○ 2.
- ○ 3.I am struggling with my beliefs and religion.
- ○ 4.
- ○ 5.I am at peace with my child's conditon and my religious beliefs

40. Do you have the child care you need?
- ○ 1.Appropriate affordable child care is a very big problem for me.
- ○ 2.
- ○ 3.Child care is somewhat a concern.
- ○ 4.
- ○ 5. Child care is never a concern.

41. Can you choose to stay-at-home or work outside the home if you want to?

○ 1.I have no choice, I either am working because I have to or staying home because I have to.

○ 2.

○ 3.I have some choice and some support in my decision to work or stay at home.

○ 4.

○ 5.I can choose to either work or stay at home and I have all the support I need.

APPENDIX 5

12-1-05 Parent Themes

1. Access to Existing Health Care & Other Services

a. access - access to doctor important
b. access - access to services difficult
c. access - conflict between TRICARE and schools on coverage
d. access - everything is a fight
e. access - fear of not getting needed services
f. access - flexibility important
g. access - inflexible rules cause difficulties
h. access - limited Medicaid waiver access
i. access - military health care system inconsistent
j. access - need doctors who know the system
k. access - no continuity of care
l. access - not enough time with physicians
m. access - preventive care hard to get
n. access - services inconvenient
o. access - system makes parents work harder
p. access - transition barriers

2. Relationships & Communication with Providers

a. comm - comm across cultures
b. comm - empathy for health care providers
c. comm - have to force conversations with doctors
d. comm - insensitive comments or actions traumatic
e. comm - language barrier
f. comm - listen to parents
g. comm - need information about the moment of death
h. comm - need to know how to communicate under high stress
i. comm - scared of asking questions
j. comm - importance of sensitivity, care & support from providers
k. comm - providers not always right or fully honest, parents feel betrayed

3. Emotional Toll on Parents & Family

a. emot relat toll - child excluded socially
b. emot relat toll - close to the edge emotionally
c. emot relat toll - constant stress
d. emot relat toll - fear of asking for community support
e. emot relat toll - huge emotional toll
f. emot relat toll - impacts whole life
g. emot relat toll - need control over information what to expect
h. emot relat toll - need help with emotional toll
i. emot relat toll - no one knows what to say when child dies
j. emot relat toll - relationship issues
k. emot relat toll - stress of providing support

l. emot relat toll - tired of fighting

4. Military Issues
a. military - command needs to know what to do
b. military - conflict between military and family
c. military - influence of military rank

5. Survivors
a. need care for child survivors

6. Advocacy
a. advocacy - parents advocate for children
b. advocacy - parents do not know system
c. advocacy - parents need advocacy education
d. advocacy - parents need help advocating

7. Decision Making
a. DM - hard to get information for shared decision making
b. DM - need preparation for decisions near time of death
c. DM - SDM with clear guidelines
d. DM - shared decision making important
e. DM - want inclusion in decisions
f. DM - want information to make decisions
g. DM - sometimes want someone else to make decisions
h. DM - have to make difficult or risky decisions for child for qol

8. Meaning
a. seeking to find positive meaning for child's life
b. seeking to find positive meaning for their own lives

9. Parents' Roles
a. parents' roles - vigilance because children are physically vulnerable
b. parents' roles - need to maintain constant vigilance
c. parents' roles - taking care for other family members
d. parents' roles - taking care of self

10. Recommendations for the system
a. rec - staff development about helping parents with the time of death
b. rec - staff need support
c. rec - staff development to understand children and families
d. rec - learn from other programs that are working well

11. Care Coordination
a. care coord - case management important
b. care coord - lack of coordination of care between physicians

c. care coord - resources outside the military health system

12. Mental Health
a. MH - need bereavement care
b. MH - whole family needs support

13. Palliative Care
a. palliative care - palliative care important
b. palliative care - try to improve children's quality of life

14. Respite
a. respite - respite care

APPENDIX 6

BENEFITS AVAILABLE IN TRICARE/CHAMPUS FOR CHILDREN WITH LIFE THREATENING ILLNESSES AND THEIR FAMILIES

Respite Care

BENEFIT	CITATION	DESCRIPTION OF BENEFIT	COMMENTS	GAP
Respite care	TRICARE Extended Care Health Option (ECHO). Final Rule/FR Vol 69, No 144, Jul 28, 2004	**(c)**(7) Respite care. ECHO beneficiaries are eligible for 16 hours of respite care per month in any month during which the qualified beneficiary otherwise receives an ECHO benefit(s). Respite care is defined in Sec. 199.2. Respite care services will be provided by a TRICARE-authorized home health agency and will be designed to provide health care services for the covered beneficiary, and not baby-sitting or child-care services for other members of the family. The benefit will not be cumulative, that is, any respite care hours not used in one month will not be carried over or banked for use on another occasion.	*Pending signature and contract modifications.* Part 199.2 Definitions (b) Specific definitions. Mental retardation = A diagnosis of moderate or severe mental retardation make in accordance with the criteria of the current edition of the "Diagnostic and Statistical Manual of Mental Disorders" published by the American Psychiatric Association. Serious physical disability = Any physiological disorder or condition or anatomical loss affecting one or more body systems which has lasted, or with reasonable certainty is expected to last, for minimum period of 12 contiguous months, and which precludes the person with the disorder, condition or anatomical loss from unaided performance of at least one Major Life Activity as defined in this section. Extraordinary condition = A complex clinical condition, which resulted, or is expected to result, in extraordinary TRICARE/CHAMPUS costs or utilization, based on thresholds established by the Director, OCHAMPUS, or designee. Extraordinary physical or psychological condition = A complex physical or psychological clinical condition of such severity which results in the beneficiary being homebound as defined in this section. Homebound = A beneficiary's condition is such that there exists a normal inability to leave home and, consequently, leaving home would require considerable and taxing effort….Absences…for the purpose of attending an educational program…shall not negate the beneficiary's	Available only for TRICARE-eligible family members of active duty service members. Network inadequate.

			homebound status. Major Life Activity = Breathing, cognition, hearing, seeing, and age appropriate ability essential to bathing, eating, grooming, speaking, stair use, toilet use, transferring, and walking. Respite care = Respite care is short-term care for a patient in order to provide rest and change for those who have been caring for the patient at home, usually the patient's family. Government cost-share maximum monthly benefit of $2,500.	
	Part 199.5 – TRICARE Extended Care Health Option (ECHO), Jul 28, 2004. **(e)ECHO Home Health Care (EHHC).**	**(e)**(2) EHHC beneficiaries whose plan of care includes frequent interventions by the primary caregiver(s) are eligible for respite care services in lieu of the ECHO general respite care benefit. For the purposes of this section, the term "frequent" means "more than two interventions during the eight-hour period per day that the primary caregiver would normally be sleeping." The services provided…are those that can be performed …by the average non-medical person…after has been trained by appropriate medical personnel. EHHC beneficiaries in this situation are eligible for a	**(e)**(3) EHHC eligibility. Beneficiaries meet all ECHO eligibility requirements and who: (ii) are homebound; (iii) require medically necessary skilled services that exceed the level of coverage provided under the Basic Program's home health care benefit; (iv) or require frequent interventions by the primary care giver(s) such that respite care services are necessary to allow primary caregiver(s) the opportunity to rest, and are case managed to include reassessment at least every 90 days and receive services as outlined in a written plan of care; and (vi) receive all home healthcare services from a TRICARE-authorized home health agency as described in Sec 199.6(b)(4)(xv), in the beneficiary's primary residence. **(e)**(4) EHHC plan of care. A written plan of care is required prior to authorizing ECHO home health care. The plan must include the type, frequency, scope and duration of the care provided and support the professional level of the provider.	

		maximum of eight hours per day, 5 days per week, or respite care by a TRICARE-authorized home health agency.		

Home Health Care

Home health care	Part 199.5 – TRICARE Extended Care Health Option (ECHO) July 28, 2004	**(e)**(1) ECHO Home Health Care (EHHC). Home health care. Covered ECHO home health care services are the same as, and provided under the same conditions as those services described in Sec 199.4, except that they are not limited to part-time or intermittent services. **(f)**(3)(ii) ECHO home health care. The maximum annual Government cost-share for ECHO home health care, including EHHC respite care may not exceed the local wage-adjusted highest Medicare Resource Utilization Group (RUG-III) category cost for care in a TRICARE-authorized skilled nursing facility.	Basic Program. 199.4(e)(21)(1) Home health services. Home health services are covered when furnished by, or under arrangement with, a home health agency (HHA) that participates in the TRICARE program and provides care on a visiting basis in the beneficiary's home. Covered HHA services are the same as those provided under Medicare under section 1861(m) of the Social Security Act. …Benefit coverage…part-time or intermittent skilled nursing care, physical therapy, speech-language pathology, and occupational therapy, medical social services, part-time or intermittent services of a home health aide, medical supplies, a covered osteoporosis drug, and durable medical equipment, services at hospitals, SNFs or rehabilitation centers.	Network inadequate.

Custodial Care

Custodial care	Part 199.5 – TRICARE Extended Care Health Option (ECHO) July 28, 2004	**(e)**(1)…Custodial care services, ad defined in Sec. 199.2, may be provided to the extent such services are provided in conjunction with authorized ECHO home health care services, including the EHHC respite care benefit.	Custodial care services may be provided only as specifically set out in ECHO.	

Counseling Services

Bereave-ment care			Excluded in hospice care through Basic Program.	
Counseling for child	Part 199.4 – Basic Program	(ix) Treatment of mental disorders….the patient must be diagnosed by a CHAMPUS-authorized …mental health professional to be suffering from a mental disorder…in order for treatment of a mental disorder to be medically or psychologically necessary, the patient must, as a result of a diagnosed mental disorder, be experiencing both physical or psychological distress and an impairment in his or her ability to function in appropriate occupational, education, or social roles.		
Counseling for family members before child's death	Part 199.4 – Basic Program	(ix) Treatment of mental disorders….the patient must be diagnosed by a CHAMPUS-authorized …mental health professional to be suffering from a mental disorder…in order for treatment of a mental disorder to be medically or psychologically necessary, the patient must, as a result of a diagnosed mental disorder, be experiencing		

		both physical or psychological distress and an impairment in his or her ability to function in appropriate occupational, education, or social roles.		

Care Management/Care Coordination Services

Care co-ordination				
Nursing case manage-ment				

Hospice

Hospice	Part 199.4 – Basic Program	(19) Hospice Care. Hospice care is a program which provides an integrated set of services and supplies designed to care for the terminally ill. This type of care emphasizes palliative care and supportive services, such as pain control and home care, rather than cure-oriented services provide in institutions that are otherwise the primary focus under CHAMPUS. The benefit provides coverage for a humane and sensible approach to care during the last days of life for some terminally ill patients. (i) Benefit coverage. CHAMPUS beneficiaries who are terminally ill (that is, a life expectancy of six months or less if the disease runs its normal course) will be eligible for the following services and supplies in lieu of most other CHAMPUS benefits: (A) Physician services. (B) Nursing care. (C) Medical social services …(1) Assessment of social and emotional factors …(2)	Part 199.6 Authorized providers. Hospice programs. Hospice programs must be Medicare approved and meet all Medicare conditions of participation (42 CFR part 418) in relation to CHAMPUS patients in order to receive payment under the CHAMPUS program….May be either a public agency or private organization which: (A) is primarily engaged in providing care and services described under Sec 199.4(e)(19) and makes such services available on a 24-hour basis. (B) Provides bereavement counseling for the immediate family or terminally ill individuals. (C) Provides for such care and services in individuals' homes, on an outpatient basis, and on a short term inpatient basis, ….(4) Have an interdisciplinary group composed of (i) physician; (ii) registered professional nurse; (iii) social worker; (iv) pastoral or other counselor. (5) Maintains central clinical records on all patients. (7) The hospice and all hospice employees must be licensed in accordance with applicable Federal, state and local laws and regulations.	Must meet Medicaid definition of hospice care.

		Assessment of relationship between …requirements and availability of community resources. (3) Appropriate action to obtain available community resources to assist in resolving the beneficiary's problem. (4) Counseling services that are required by the beneficiary. (D) Counseling services provided to the terminally ill individual and the family member or other persons caring for the individual at home…Bereavement counseling is not reimbursable. (E) Home health aide services … and homemaker services.		

Additional Services

Child life services at home				
Massage therapy				
Music therapy				
Acu-puncture				

Durable equipment and durable medical equipment	Part 199.5 – TRICARE Extended Care Health Option (ECHO) July 28, 2004	**(g)**(2) Equipment (i) The TRICARE allowable amount for durable equipment and durable medical equipment shall be calculated in the same manner as durable medical equipment allowable through Sec. 199.4. (ii) Allocating equipment expense. The ECHO beneficiary…may, only at the time of the request for authorization of equipment, specify how the allowable cost of the equipment is to be allocated as an ECHO benefit. The entire allowable cost…may be allocated in the month of purchase…or may be prorated. **(c)**(7)(ii) Equipment adaptation. The allowable equipment purchase shall include such services and modifications to the equipment as necessary to make the equipment usable for a particular ECHO beneficiary. (iii) Equipment maintenance. Reasonable repairs and maintenance of beneficiary owned or rented durable	Part 199.2 –Definitions. Durable equipment. A device or apparatus which does not qualify as durable medical equipment and which is essential to the efficient arrest or reduction of functional loss resulting from, or the disabling effects of a qualifying condition. Durable medical equipment. Equipment for which the allowable charge is over $100 and which: (1) Is medically necessary for the treatment of a covered illness or injury; (2) Improves the function of a malformed, diseased, or injured body part, or retards further deterioration of a patient's physical condition; (3) Is primarily and customarily designed and intended to serve a medical purpose rather than primarily for transportation, comfort or convenience; (5) Provides the medically appropriate level of performance and quality for the medical condition present.	

		equipment or durable medical equipment provide by this section shall be allowed while a beneficiary is registered in ECHO.		
Structural alterations to dwelling	Part 199.5 – TRICARE Extended Care Health Option (ECHO) July 28, 2004	**(d)**(3) Structural alterations. Alterations to living space and permanent fixtures attached thereto, including alterations necessary to accommodate installation of equipment or to facilitate entrance or exit, are excluded.		

APPENDIX 7

DRAFT PROGRAM "RULES" FOR MCARE

Comments and Questions:

1. Can hospital commander authorize payment for a benefit that is not authorized in the policy manual?

   a. Maybe the pilot at WRAMC/NNMC will need to be a limited demo to get the authority to buy services such as respite care, case management, and bereavement care for which the child may not be eligible under the current TRICARE benefit structure.

2. Whether or not we need to write a proposed rule, i.e., new chapter for the policy manual, we need to describe the new program we are asking the hospital commanders to implement, being sure to include the QA features that the MHS uses (i.e., Medicaid or TRCARE approved home health agencies).

3. How is care coordination billed, paid for in the civilian community? Will we be able to justify a pediatric palliative care coordinator (to augment Deb and the NICU discharge planners) in the pilot that could be recognized in the "rule" as a service that can be purchased? I think this person could be either a nurse or social worker.

4. I'm not sure that some of the boiler plate for eligibility isn't because the ECHO is limited to active duty. Anyway, it seems reasonable to continue services for children whose sponsor dies on active duty for 3 yrs, or under hostile fire until age 21.

5. Will claims from the home health agency or equipment vendor go through the usual channels or will they be handled differently in the pilot? If they go through the usual route, we'll need to modify the codes that can be paid.

6. How does the MHS reimburse a family member for services? Who is a family member (sibling, grandparent, aunt, etc)?

7. What is the appeal mechanism if the care coordination team does not agree on something in the plan of care? Can the portions agreed upon be implemented? Does the plan of care need to be approved by someone else before government funds are committed? Who is that someone else and how long will it take?

mCARE
Integrated Palliative Care Program For Children With Life-Threatening Illnesses.

(a) General. (1) The TRICARE mCARE is a supplement to the Basic Program. It does not provide acute care nor benefits available through TRICARE Basic Program. mCARE benefits are available to children of active duty and retired sponsors. There is no cost-share liability to the sponsor nor a maximum monthly government liability.

(2) The purpose of mCARE is to provide a mechanism to coordinate and integrate palliative care, disease-directed care, and support for children with life-threatening illnesses and their families from diagnosis through treatment with hope for a cure to bereavement care if a cure is not obtained. Care provided through the mCARE program will be continuous, comprehensive, coordinated, family-centered, culturally-competent, and medically appropriate. It expands the benefits available to a child with a life-threatening illness and their family to include services defined in a Medicaid-approved pediatric hospice program.

(b) Eligibility. (1) The following categories of TRICARE/CHAMPUS PRIME beneficiaries with a qualifying condition are eligible for mCARE benefits.

(i) A child (as described in 10 U.S.C. 1072(2)(A),(D), or (I)) of a member or one of the Uniformed Services; or

(ii) An abused dependent child as described in Section 199.3(b)(2)(iii); or

(iii) A child (as described in 10 U.S.C. 1072(2)(A),(D), or (I)) of a member of one of the Uniformed Services who dies while on active duty. In such case the child remains eligible for benefits under the mCARE program for a period of three years from the date the active duty sponsor dies; or

(iv) A child (as described in 10 U.S.C. 1072(2)(A),(D), or (I)) or a deceased member of one of the Uniformed Services, who, at the time of death was eligible for receipt of hostile-fire pay, or died as a result of disease or injury incurred while eligible for such pay. In such case, the child remains eligible through midnight of the beneficiary's twenty-first birthday.

(2) Qualifying condition. Children will be determined to have a life-threatening qualifying condition by their primary care physician in coordination with their parents. The following are examples of qualifying conditions:

(i) Children with diseases for whom treatment is available, but may not be successful.

(ii) Children for whom aggressive treatment is available that may result in a good quality of life, but who, nevertheless, will die prematurely.

(iii) Children with progressive diseases who may live for prolonged periods of time.

(iv) Children with severe disabilities that are not progressive, but will likely lead to complications and premature death.

(3) Loss of mCARE eligibility. Upon separation from the service.

(c) mCARE benefit. Services that the Director, TRICARE management activity, or designee has determined are capable of ensuring the provision of an integrated program of palliative care, disease-directed care, and support as determined appropriate by the child's primary care physician and the family, includes, but are not limited to:

(1) Care coordination. Care coordination will be provided by a pediatric palliative care coordinator and will implement a comprehensive plan of care. Care coordination may be provided by the MTF or purchased from a TRICARE-approved home health agency or agency that coordinates care for CMS MEDICAID waiver programs and that has pediatric-trained and experienced staff. Care coordination is necessary to receive other benefits under this program.

(i) A written comprehensive plan of care will be developed within 2 weeks of referral to the mCARE program. The plan of care will include all services, durable medical equipment, and durable equipment necessary to address medical, social, educational, spiritual needs of the child, and support services for the family, although not all these services or equipment are necessarily purchased or provided through the MHS unless provided for below. The plan of care will be reviewed at least every 3 months and updated as needed. The written comprehensive plan of care will be developed by a team including the care coordinator, the parents, the child if appropriate, and the child's primary care physician and appropriate specialty care physicians.

(ii) A copy of the plan of care will be placed in the child's medical record, a copy provided to the parents, and a copy forwarded to the mCARE program manager at the MTF.

(iii) The plan of care will specify an emergency plan of action for the parents or school.

(iv) The plan of care will address the support a family requires when two or more family members have special needs.

(v) Parents and physicians will have access to educational materials preparing them for their role on the care coordination team.

(2) Respite care. mCARE beneficiaries are eligible for respite care for a maximum of eight hours per day, 5 days per week provided by a TRICARE-approved home health agency. In addition, two consecutive 24-hour periods per month may be provided. The level of training required by the respite care provider will be specified in the plan of care.

(3) Pre-bereavement and bereavement counseling. Counseling will be provided to the child and family as defined in the plan of care. A diagnosis of mental illness is not necessary for the child or any family member in order to qualify for this service. The level of training of the counselor will be specified in the plan of care.

(4) Home health care. Home health care will be provided as described in the plan of care. The level of training of the provider will be specified in the plan of care and may include any or all of the following: registered nurse, licensed practical nurse, personal attendant. Services are not limited to part-time or intermittent. The services of a registered nurse are not necessary to receive this benefit. If home health care is provided by a family member, that family member will be reimbursed for up to 40 hours per week at the same rate as a personal care attendant in a local TRICARE-approved home health agency.

(5) Custodial care. Custodial care is authorized under mCARE. If custodial care is provided by a family member, that family member will be reimbursed for up to 40 hours per week at the same rate as a personal care attendant in a local TRICARE-approved home health agency.

(6) Inpatient pediatric hospice services. Inpatient pediatric hospice services may be purchased when provided in a TRICARE-approved hospice program or a MEDICAID approved pediatric custodial care facility. A written plan if care is required and bereavement counseling services must be provided.

(7) Durable medical equipment and durable equipment. Durable medical equipment and durable equipment specified in the plan of care will be purchased by the MHS as provided for in Sec. 199.4 (?)

(8) Transportation. Specialized medical transportation (ambulance or taxi accommodating wheelchairs) will be purchased by the MHS when specified in the plan of care and necessary for the child to travel to and from the hospital or clinic.

(9) Structural alterations. As specified in the plan of care, up to $1000 per child may be reimbursed to the family by the MHS for structural alterations necessary to provide care to the child in the family home.

(10) Coordination during PCS moves and deployments. The written plan of care will address the increased need for support a family faces during PCS moves or deployments when caring for a child with a life-threatening illness. The plan of care will provide for a seamless transition to the gaining medical facility.

(11) Expressive therapies. As defined in the written plan of care, expressive therapies such as music therapy, art therapy, and play therapy are authorized when provided by licensed or registered therapist.

(d) mCARE Exclusions. Benefits provided under the TRICARE Basic Program will not be provided through mCARE. These benefits will, however, be specified and coordinated in the written plan of care.

APPENDIX 8

Community Resources for Children with Life Threatening Conditions

Children's Hospice Project

12/21/05

Prepared by,

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The Coordinating Center

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Background

Children of families in the military who have life threatening conditions can benefit from access to community resources to support their medical, educational, rehabilitation, social and emotional needs. The Coordinating Center studies community resources with a focus on types of resources available, access to resource information as well as the identification of any other factors that may have an effect on utilization of such services. Findings related to community resources will be used to inform other aspects of the Children's Hospice Project. The goal of the work performed by The Coordinating Center is to identify opportunities to improve access and utilization of community resources for children in the military under a model of care that is consistent with the philosophy of CHI/PACC™ models of palliative care. [1]

The Coordinating Center evaluates community resources that may be available to children of military families the National Capital Area (NCA). As part of this evaluation, The Center examines types of existing community-based services, as well as their availability from several perspectives including location and accessibility. The primary purpose of this evaluation is to identify opportunities for utilization of services that exist outside of the scope of the military

[1] The CHI/PACC™ philosophy and model is a palliative care model promoted by Children's' Hospice International and is designed to manage medical, spiritual and psychological services needed by families to care for children and adolescents diagnosed with life-threatening and potentially life limiting conditions, from the time of diagnosis, with hope for a cure, through end of life care, and to bereavement follow-up.

health care system that may be unknown to or underutilized by families. Ideally, the project will lead to the development of an optimal model of care that ultimately supports families in the military and military readiness[2].

The national agenda promotes the delivery of family - centered services to children with chronic conditions.[3] To be consistent with these initiatives, this community resource component of the Children's Hospice Project will incorporate considerations for resources that support family as well as the child with a life limiting condition. In addition, resource types will focus on those that may address needs of the family and child along the continuum, from time of diagnosis, through critical points during their lives, and at the end of life. The same philosophy is embraced by the CHI/PACC™ philosophy, which is to assist children and families within their homes and communities and to support the independence and care giving functions of the families through access to services and resources in the community and home. Additionally, the Department of Defense expresses significant interest in the concept of military readiness. This concept incorporates a comfort level of the soldier or officer that their family will be safe and provided for during episodes of military deployment. Therefore services that support the needs of the military family can be considered to support the military readiness of the soldier. Military parents may experience additional anxiety related to episodes of deployment if there are inadequate supports in place for their family and children while they are absent. This is particularly significant when a parent is deployed and leaving a child who has a life threatening illness.

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2 The Congressional Budget Office (CBO) uses the Joint Chiefs of Staff's definition of readiness, which is also referred to as operational or current readiness: the ability of forces to deploy quickly and perform initially in wartime as they were designed. (Joint Chiefs of Staff, The Dictionary of Military and Associated Terms, Joint Publication 1-02 (March 23, 1994)

[3] The American Academy of Pediatrics supports this concept of family-centered care through their medical home initiatives. http://www.medicalhomeinfo.org/about/index.html

The Coordinating Center focuses on community based resources existing in the five-catchment areas representing the National Capitol Area as listed below:

- WRAMC
- Fort Detrick
- Fort Meade
- Fort Belvoir
- Aberdeen Proving Ground

The process used by The Coordinating Center to address the community resource evaluation includes a broad literature review, collection and analysis of resources found to exist in the 5 catchments areas listed and analysis of processes used to access resource information. It is anticipated that the process will yield some answers to the following questions related to resources. The questions are:

- What types of supports are available to children with life threatening condition and their families?
- Where is information about community resources located?
- What is the process for accessing community resource information?
- What are some of the barriers for families in identifying and finding resource information?
- What strategies can be incorporated in a new model design to optimize access to information about community resources?

Resource Review

A literature review is conducted to learn more about the broad subject of community resources, and describe the experience of finding and accessing resource services to ultimately support children with life threatening conditions and their families. For the purposes of this review, the working definitions are as follows:

- Community - A group of people living in the same locality and under the same government; the district or locality in which such a group lives; a group of people having the same interests.[4]
- Resource - Something that can be used for support or help, or an available supply that can be drawn on when needed; means that can be used to cope with a difficult situation.[5]

Of necessity, these definitions are broad and subject to individual connotation. The broad-based definitions also accommodate the unique family perceptions of what is or is not supportive in the community in a particular situation. Considering the potential for omitting possible helpful supports to families from an inpatient and community standpoint, this report will incorporate the broad definitions as the basis for the study. Obviously, with such broad definitions, any one study may not feasibly capture every possible community resource in the areas identified. Therefore, additional searches for resources may need to occur once the specific population for Children's Hospice Project has been determined and their needs assessed through focus groups. It is anticipated that this exercise of reviewing community resources will demonstrate some trends and commonalties about the topic.

Sources and search parameters

The literature review was implemented at The University of Maryland Health Science Library, local public libraries, Fort Meade library used only by military families as well as other less formal community locations such as non professional journals, local newspapers, pediatrician office brochures, local health department information and at local community fairs. The initial search for information on resources was at the University of Maryland Health Science Library used by medical professionals such as nurses, physicians, and social workers. Multiple

[4] Definition from Dictionary.com, 2004
[5] Definition from Dictionary.com, 2004

database searches were performed with various search words used. Assistance was obtained by trained library staff to identify the most appropriate search words as well as the most appropriate databases for which to search. The following table depicts the results of the search.

Database	**Search Words**	**Results**	**Related to Children's Hospice Community Resource**
Social Work Abstracts 1997-2003	Children Programs and Services	87	21
CINAHL 1982 - 2003	Children Programs and Services	119	42
CINAHL 1982 - 2003	Care and Services for Terminal Illness	53	14
Psych Info	Hospice and Palliative Care Services	12	7
Psych Info	Children Program and Services	139	41
Directory on Disc*	Searches are pre-defined through categories of resource information		Results relate to specific category queried

Directory on Disc[6] is a community information database designed to assist communities in finding information and services to provide an entry point for social assistance. This database provides information related to relationship issues, domestic violence, suicide, mental health concerns, substance abuse, grief, pregnancy, rape, abuse, crisis, housing assistance, disabilities, teen concerns, youth behavior problems and community information and referrals.

Following the review of literature at the Health Science Library, extensive Internet searches were performed with the following search results:

[6] Directory on Disc is a product of 2-1-1 Big Bend, founded in 1970 as an independent non profit organization widely respected and recognized as a leading resource for confidential hotline support services and provides a free searchable resource database at www.211bigbend.org . United Way of the Big Bend has been the primary funding source.

Search Word	Search Engine	Results of Query	Possible applicability of Information found on 1st 10 pages of result review
Community Resources	Google	33,300,000	Search results are too variable for usefulness
Community Resources	Yahoo	44,700,000	Search results are too variable for usefulness
Children and Hospice	Google	1,200,000	Specific Hospices and General Information on Hospice and Children/Parents Dying
Children and Disabilities	Google	9,1800,000	General Information on Disabilities
Children Programs and Services	Google	21,000,000	National Programs/State and County Hospitals
Hospice and Palliative Care Services	Google	302,000	Specific Hospices and General Information on Hospice
Children and Terminal Illness	Google	541,000	Specific National/State Resources and Literature Reviews
Community Resource	MSN	9,649,923	Search results are too variable for usefulness
Children and Hospice	MSN	168,362	Specific Hospices and General Information on Hospice and Children/Parents Dying
Children and Disabilities	MSN	841,002	General Information on Disabilities
Children Programs and Services	MSN	2,169,473	Overview of Services Available/National Programs
Hospice and Palliative Care Services	MSN	31,138	Specific Hospices and General Information on Hospice
Children and Terminal Illness	MSN	67,406	Literature Reviews and Generic Information for Parents, Siblings and Classmates
Community Resource and chronic conditions	Yahoo	1,730,000	Condition specific Information, Community Databases

Responses and Challenges in Resource Development

One of the challenges experienced while performing the literature review on community resources is the unmanageable volume of responses to Internet and Database searches. The literature search, in some ways mimics some of the ways that families go about trying to locate information about resources for their children with life threatening conditions. Therefore, at

least some of the challenges that we encountered would be similar to those that are encountered by families. The primary challenge identified through this exercise of searching for community resources and related literature is the overwhelming number of search responses that created an unmanageable volume of information. For example, in Internet research, when we typed the key phrase "community resource" 44,700,000 websites were returned. When we used the keywords "children with life- threatening illnesses" 541,000 websites were cited. Similar phenomena occurred when we searched the HSL databases on the topic. A strategy to reduce the search to more manageable result is to be more specific about the resource being sought. This ability to search for specific keywords to locate resources has implications related to a family's level of skill related to querying the Internet. This strategy could be used if families had the information and confidence to query on a specific resource.

A second challenge with the initial literature review was the ratio of time spent and value attained through data searches. Sorting through a high volume of information to find potentially useful resources is extremely time consuming. Often, the significant time spent yielded minimal return in terms of meaningful and targeted information. Keeping in mind that children with life threatening conditions have time intensive needs, including frequent appointments to physicians, and complex medication and treatments regimens, this kind of search seems to be an unreasonable expenditure of time for families caring for their child with complex needs. In fact, when parents are dealing with a child who is hospitalized, they have indicated that they feel emotionally torn between providing constant support to their hospitalized child and caring for their other children at home [7]. Assuming these parents and those who are primary caregivers in the home have time to sort through volumes of information to find effective supports may be an unreasonable expectation. In addition to time spent locating information regarding resources,

[7] Melnyk and Alpert-Gillis, 1998

some resources require additional time and effort to obtain and complete an application for the desired service. In some instances such as Grant a Wish, Supplemental Security Income (SSI) or application for developmental disability services, there is a requirement for physician documentation and signature. For families, who are in desperate need of support and services, the process may pose barriers that prevent the family from ever accessing the desired support.

In relation to military families, who are dealing with stresses associated with single parenting and deployment, additional time and steps add yet an additional layer of action to successfully access the needed service.

While the Internet has become one of the most widely used communication media, assessing the credibility of the publisher as well as the relevance and accuracy of a document retrieved from the Net can be a problem. With the availability of Web server software, anyone can set up a Web site and publish any kind of data, which is then accessible to all. The Health on the Net (HON) Foundation has elaborated the Code of Conduct to help standardize the reliability of medical and health information available on the World Wide Web. The HON code defines a set of rules to hold Web site developers to basic ethical standards in the presentation of information and help make sure readers know the source and purpose of the data they are reading. [8] In some situations, web sites reviewed provide no appropriate documentation regarding the credibility, currency or accuracy of the information they are presenting.

As part of the search exercise, contacts were made at the local public libraries and a military specific library to determine the availability of resources and information as well as the process to conduct searches performed for and by families. While there are multiple databases offering resource information, there are also resource guides, stocks of pamphlets in health centers and physician offices, flyers and fact sheets found in libraries, schools and military

[8] http://www.hon.ch/HONcode/Conduct.html

treatment centers, much of the information is vague as to details of service and mechanisms for funding the service. Some resources found in pamphlet information were identified to be no longer relevant or programs and services that were no longer funded. This phenomena may be attributed to the services advertised and funded by less stable sources, such as foundations, short term demonstration projects or under funded public programs. As traditional helping organizations reflect the economic situation in the country, the capacity of funders and foundations to continue to achieve their missions in the community may be affected. In some situations, this may lead to longer waiting lists for services and curtailed or lost services for families and children. The military family is not immune from this phenomenon.

A publication cited to be the single largest and most widely referred to directory in the disability field is Exceptional Parent (EP) magazine.[9] This publication has been in existence for over 35 years. Exceptional Parent magazine is published monthly and includes one special January issue each year that is the EP Annual Resource Guide. This annual guide includes comprehensive directories of organizations, associations, products and services for the special needs communities. The monthly publication is designed to provide information and support for parents, families, physicians and professionals who are supporting people with special needs. In addition to the publication, the information is also accessible through subscription on-line. Cost of this publication is approximately $35.00 for the first year subscription.

There is an emotional toll on families of children with life threatening conditions that may affect their capacity to reach out for assistance. The literature sheds light on the fact that families caring for severely disabled children with complex health care needs experience extraordinarily high levels of responsibility in the absence of sustained support.[10] Thus, families,

[9] www.eparent.com
[10] Robinson, Jackson and Townsley, 2001

as the primary managers of their children's care, are often the primary seekers of assistance and information as well. Yet, there are critical times in the child's situation when the emotional responses of families work against their capacity to function effectively in this area. For example, when children are hospitalized, especially for unplanned admission, or their situation changes negatively, some parents may experience anxiety and sometimes panic. At such times, their own behaviors may reflect disequilibrium, disorganization, vulnerability and even psychosomatic symptoms. Expressions of denial, anger, protest, guilt and sadness, and mourning typically follow these initial reactions.[11]

The family experience may be exacerbated when there are other children in the family and particularly in military families should they occur when the spouse is deployed outside the home jurisdiction. If a family is relocated due to military responsibility, this will typically include a change in healthcare providers. Often families have established relationships with providers who are familiar with their child's care and are then in a situation that they must establish new relationships with new providers and services.

The Exceptional Family Member Program (EFMP)[12] is one example of a military specific program for all active duty service members providing personnel function and a family support function. The EFMP personnel function is a mandatory program for all active duty service members and is standard across all services. The purpose is to identify military personnel who have a family member with special medical and/or educational needs, document the services they require and consider those needs during the personnel assignment process. This function involves the personnel and medical commands and the Department of Defense educational

[11] Melnyk and Alpert-Gillis, 1998

[12] EFMP description obtained from Military HOMEFRONT, a web based resource described as the central, trusted, up to date source for service members and their families to find information about all DoD quality of life programs and services.

system overseas. Unlike the personnel function, the EFMP family support function is not mandatory. The Department of Defense (DoD) allows, but does not require, the Military Services to offer family support services to exceptional family members. Consequently, this practice differs from service branch to service branch. In the Army and the Marine Corps, family centers are staffed with individuals whose responsibility is to provide support to families with exceptional family members. They are called EFMP Coordinators. In the Navy, the EFMP staff who support the Personnel Function may also provide family support services, but the Navy does not staff their family centers with EFMP Coordinators. In the Air Force, the Special Needs staff are located in the Military Treatment Facility (MTF) only. The EFMP Re-Assignments Branch is a personnel function. Family Support Center staff provides Family Life Education, Information and Referral and Personal Finance Management services but do not have a designated Coordinator.

A recurring theme in the literature is that parents express the significance of maintaining the role of decision-maker and be seen as pivotal in the effort to locate and use resources to benefit their children with life threatening conditions. Indeed, parents themselves express that among their primary concerns is the perceived loss of the parental role. [13] Yet, as health care systems grow more complex and difficult for parents and professionals to navigate, professionals are being asked to be accountable for assisting in more direct ways and they are expected to respond more effectively to the needs of families in ways that respect parental choices and decisions. To make the relationship between the family and the helping professional work on behalf of the child, open and honest communication between families and professionals,

[13] Melnyk and Alpert-Gillis, 1998

including health care providers and ancillary personnel is essential. This is especially the case when families are confronted with disappointing results, unexpected outcomes, uncertainties about their children's conditions and controversies about the direction to take on their behalf[14]

Resource Analysis in the National Capital Area

Federal and State Resources

Federal Programs for children are typically categorized under the areas of health, education, income support, mental health and social service. The federal level programs are complex, and therefore the tables contained in this document include only selected information that has been deemed relevant to children with life threatening conditions. Eligibility criteria can be very detailed and in many situations is defined broadly by federal statute, but with more detailed criteria determined by each state. Federal programs are subject to availability of funding and may change based on proposed shifts to block grants or issues of national priority.

An important factor regarding federal level programs is that many are administered at a state level. Administration of a federal program at a state level allows the state to customize the program based on each state's perceived needs and populations. As a result, these programs often have varying eligibility criteria as well as varying allowances for participation and benefits. Thus, a family may qualify for a program in one state, however if the family is relocated by request of the military, there is no guarantee that they will qualify in the other state for a similar program. This phenomenon coupled with complex or generic program descriptions and lengthy application processes may create a gap or disruption in services for children who have very complex medical situations.

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[14] Gilmer, 2002

Refer to the *Resource Description Table* (Appendix A) for further detail regarding federal, state and local community programs relevant to children with life threatening conditions. The table provides descriptions of the program types and resources provided through each specific program.

The Medicaid Program can be a significant source of support for some families who have children with special healthcare needs and meet qualifying criteria for the program. Although the Federal government establishes general guidelines for the Medicaid Program, each state establishes program requirements. The Medicaid Program provides medical benefits to low income people who have no medical insurance or inadequate medical insurance. Medicaid is the nation's largest health care program, providing health and long-term care services to 53 million low- income pregnant women, children, individuals with disabilities, and seniors. Whether or not a person is eligible for Medicaid will depend on the State where he or she lives. States are required to include certain types of individuals or eligibility groups under their Medicaid plans and they have the option to include others. The states' eligibility groups are considered to fit one of the following categories: categorically needy, medically needy, or special groups. [15]

In addition to the Medicaid program, states have a health insurance program for children up to age 19, State Children's Health Insurance Program (SCHIP). These programs are for children whose parents have too much money to be categorically eligible for Medicaid, but no enough to buy private insurance. Most states offer this insurance coverage to children in families' whose income is at or below 200% of poverty level. However, states have different eligibility requirements. Not all the insurance programs provide the same benefits, but they all

[15] For further information regarding specific state Medicaid eligibility see http//www.cms.hhs.gov/Medicaid/eligibility

include immunizations and care for healthy babies and children at no cost. Families may have to pay a premium or a co-payment for other services depending on their income. [16] The SCHIP Program may not be a relevant resource for military families if the child already has access to Tricare.

Medicaid is a vital health care safety net and provides important services to those who cannot obtain care from any other source. Medicaid coverage is also critical for reducing the number of the uninsured currently estimated at 45 million nationwide. Medicaid spending, however, has increased dramatically over the last 5 years, driven by a 40 percent increase in caseload and a 4.5 percent per year increase in the health care price indes, strengthening the impetus for reform. According to the National Governors Association Preliminary Report dated June 15, 2005, comprehensive Medicaid reform may focus on reforming Medicaid and on strengthening other forms of health insurance and long-term care coverage.

This potential for Medicaid reform may have implications for states designing home and community based waivers such as the CHI/PACC™ models. Home and community based services are reported to be under fiscal crisis as Medicaid long term care expenditures are projected to increase. Some are concerned that the fiscal crisis may impede the growth of Home and Community Based Waiver Programs. In addition, in states where state waiver programs exist, there are long waiting lists for the programs. [17] Of eight states identified in a Kaiser funded study, a wait time for the home and community based waiver programs range from unknown to 31 months.

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[16] Dept. of health and Human Services, Centers for Medicare and Medicaid Services and Center for Medicaid and State Operations, Medicaid at a Glance 2003, A Medicaid Information Source.

[17] Information presented at the GSA Annual Meeting in San Diego Nov. 23, 2003 by Martin Kitchener PHD MBA and Charlene Harrington PhD funded by Kaiser Commission on Medicaid and the Uninsured and the The Institute for Disability and Rehabilitation Research (NIDRR)

Children's Hospice International (CHI), with technical assistance from the Centers for Medicare and Medicaid Services (CMS), Congressional Members, and healthcare leaders, developed the CHI/PACC™ programs to overcome existing barriers to appropriate care for children with life-threatening conditions and their families. These state models have applied to CMS to become Medicaid funded programs under the 1915C Medicaid Home and Community based waivers. CHI/PACC™ has received $3.2 million in federal appropriations for multi-state demonstration programs in Florida, Colorado, Utah, Virginia and additional states. Children's Hospice International has applied for additional appropriations to further CHI PACC models throughout the country in fiscal year 06. [18]

Military Resources

Children with life threatening conditions often use a myriad of medical, educational, and community based services to meet their comprehensive and complex needs. Their families, who nurture them at home, must learn to navigate systems on their children's behalf and find that they too experience needs for support as they meet the day to day responsibilities of caring for children with such challenging health concerns. In addition to the specialized health needs of these children, military families experience additional challenges requiring a spectrum of other supports. There exists a multitude of military supported programs aimed at providing resources to help active duty families. Active reserve military are also afforded resources within the military system to support some of the specific needs that military reserve families face.

Military HOMEFRONT is a web portal and described as "the central, trusted, and up-to-date source for Service members and their families to obtain information about all Department of Defense Quality of Life programs and services".[19] A systematic review of the Military

[18] http://www.chionline.org/programs/
[19] http://www.militaryhomefront.dod.mil/

HOMEFRONT website was conducted. The method used for the evaluation was identifying all topics listed on the site map. These topics were reviewed and rated based on their relevance to children with life threatening conditions. . Generally, these programs identified on this Web site address resources in the areas of transition, educational opportunity, deployment, employment issues for self and spouse, financial management, housing, family support, recreation, etc. Please refer to Appendix B*, Review of Military HOMEFRONT Web Site* for a listing of the topics and the relevance to the population.

In addition to reviewing Military HOMEFRONT, a site visit to Military One Source was conducted in 2004. Please refer to the Military One Source Report, Appendix C for further analysis of services and recommendations related to a new model design.

Other Resources

Refer to Appendix D *Community Resource Table* to see a listing of resources located in the general community of the National Capital Area. The resources have been categorized by the following topics:

- Associations and Care Organizations
- Hospitals and Health Facilities
- Hospice
- Medical Information Sources
- Government Resources
- Adaptive Technology
- Child Care
- Financial Assistance
- Medical Providers
- Hotlines
- Interpreters and Translation Services
- Mental Health
- Recreation and Camps
- Support Groups
- Transportation
- Respite Care
- Utility Assistance Programs

- Wish Granting Programs
- Special Education Information and Laws
- Home Health Care
- Durable Medical Equipment and Supplies
- Bereavement Services
- Self Esteem
- Adult Day Care
- Hearing/Visually Impaired
- Vocational/Rehabilitation Services
- Caregiver Resources
- Resource Directories
- Case Management Services
- Community Resources
- Pharmacy Programs
- Planning
- Therapeutic Services
- Literature

In addition, an extensive list of web based databases can be accessed to support children with special needs and life threatening conditions. A listing of resource databases identified in the resource review is included as Appendix E, *Web Databases Resource Directory.*

Findings and Experiences from Resource Research

The following is a list of some experiences The Coordinating Center encountered during the exercise to identify resource information. It is plausible that families may encounter similar situations in their efforts to find resource information and should be considered in developing the new model design. These experiences include but are not limited to the following:

- Difficulty obtaining information; no return phone call or contact.
- Unable to obtain information upon initial contact.
- Often transferred to another person
- Preference is to give information directly to consumer as opposed to a surrogate caller
- Home health care contact information changes frequently
- There appears to be much information regarding resources for Children with Cancer or developmental disabilities available for families on the Internet.
- Using the term *"Terminal illness"* as a keyword search often links to services appropriate for individuals with a diagnosis of Cancer rather than other life threatening conditions.
- Chapters and Associations were identified as local resources when researching specific areas in Maryland.

- Difficulty distinguishing between which category to place resource
- May find numerous programs under one agency.
- Organizations such as the Department of Social Services and Developmental Disability Administration may have different practices based on region of location within the state
- When using the Internet there appears to be very few resources that are military specific.
- Military resources are difficult to locate through civilian research.
- There appears to be inconsistencies in the resources located on military bases and those identified through the national web site.
- Military resources differ from base to base and service branch
- It is often difficult to identify the cost for the services from the information provided
- When calling an organization for resource information, you are often referred to the web site rather than providing the information over the telephone.
- Web site information is often generic and does not include the specific detail regarding the service
- Resources may be for those children and families that are already enrolled within the health care system such as Johns Hopkins - Harriet Lane Compassionate Care Program
- County libraries are available to assist in locating local community resources.
- Health care databases are located at the local libraries for public use.
- Librarians can be used to research specific questions or topics.
- Schools, camps, senior center, etc. provide the library with information related to upcoming events and general information.
- Grass root resources are more readily found through the local library rather than the Internet.
- Networking between county libraries is available
- Disease based associations can offer education and direct families toward other resources related to the diagnosis.
- Community Resource as a keyword search is too broad and yields an unmanageable number of responses
- Utilization of the search word "hospice" or "terminal" yields only end of life services and does not capture resources that may support the chronicity of palliative care patterns.
- Health Science Library results yield little as to specific resources and application for service information that could be helpful to families searching for specific service delivery
- There is an abundance of information available on the Internet attributing to results that are unmanageable due to over abundance of information that is time consuming to sort through
- Internet search results are limited by search words entered and may create barriers to families seeking information
- Web sites that identify specific services and information vary on the elements of information provided
- Some web sites do not indicate how current the information is and do not provide complete information about the resource such as funding for the service or the application process
- Website searches provided voluminous amounts of information and broader variety of possible resources
- Local public library provides assistance with searches by librarian and does not require individual to have Internet search skills or access to technology to gather basic information.
- Some local public libraries have prepared information that can be accessed on county specific services and programs as well as information on some federal programs.

- Military library at Ft. Meade provided limited information on resources in the community and referred to the local public library system
- Reliability of information received is inconsistent
- Directory on Disk is a product available at a reasonable cost to communities as a pre-designed database containing information on social assistance and tailored to the specific community. However, this is not currently available in all communities throughout the country.
- The Internet has become one of the most widely used communication media.
- The Health On the Net Foundation has elaborated the Code of Conduct to help standardize the reliability of medical and health information available on the World

Process Analysis

Locating basic information regarding a resource is typically the first step toward accessing that resource. However, the information may not be useful unless it yields actual access to the needed service. An analysis of the typical process used by an individual to access some type of a resource has been documented in the form of a data flow diagram. See Appendix F for *Data Flow Diagram*. The purpose of this is to identify possible areas of vulnerability that may preclude completion of the process to the point of service delivery. The analysis should be considered while developing the new model of care for children in the military who have life threatening conditions with attention to incorporate quality measures in the process to minimize the potential for unsuccessful service delivery.

For any typical request for resources, a professional, nonprofessional or family member may identify a need for a community resource. Then, there is some research done to identify a source for such resource to yield potential resource options to meet the resource request. This research can be done by the requestor or by another third party, such as a professional or nonprofessional invested in supporting the request. In most situations, there is some referral or application process required to access the resource. The referral or application process can vary from providing basic demographic information to extensive financial and medical reviews prior

to the approval for the resource requested. Depending on the type of resource requested, some situations will warrant the identification of a provider to deliver the resource. In some situations, further research to locate funding will be necessary prior to service delivery. Subsequent to approval for the resource, identification of the provider if applicable and identification of a funding mechanism the service delivery would occur. In some situations, reimbursement is requested following service delivery and would follow.

The basic tasks identified in this process are:

- Identification of a resource need by family, professional or other nonprofessional
- Research for possible options for desired resource
- Application to obtain resource
- Identification of a service provider
- Locating a funding source
- Delivery of the service
- Reimbursement for the cost of the service or resource

Each task within the process has been analyzed to note vulnerabilities within the process.

Process Task	Vulnerabilities
Request a resource	• Miscommunication regarding type of resource requested • Resource requested does not meet the need of the child/family • Lack of knowledge on requestors part related to type of resource needed or what may be available
Research resource options	• Resource information obtained is inaccurate or lacks correct contact information • Resource information obtained does not adequately represent what was requested
Apply for resource	• Application requires specific information that is not readily available to applicant • Application requires signature from other entity such as physician, or other professional requiring additional steps prior to completion • Application requires multiple estimates for the service requested • Poor or no direction for application completion • Application is denied based on information presented • Application gets lost during process • Application is too complex for family to complete
Identify provider for resource	• Provider will not accept reimbursement amount or method • Unable to find a provider • Provider of low quality
Locate funding source	• Unable to identify funding for resource • Not medically necessary resource • End of budget year request that will be postponed for funding in the upcoming fiscal year
Deliver resource or service	• Resource is never delivered • Resource or service is delivered but is of poor quality
Reimburse for resource or service when applicable	• Funding is delayed due to internal processes of funder • Reimbursement is required prior to service delivery • Service provider is not part of network for reimbursement

Case Management / Care Coordination

Case management is defined by the Case Management Society of America (CMSA) as "a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality, cost-effective outcomes".[20] Although third party payers and managed care programs often use the term "case management", others prefer the term "care coordination". Typically case management may include activities such as disease management, benefits management and utilization review, while "care coordination" occurs when an individualized plan of care is

[20] Definition obtained from CMSA Standards of Practice, 2002

implemented by a variety of service providers.[21] Care coordination is often the preferred term used in context of family centeredness as parents play such an integral role in the management of their child's care. Therefore, for the purposes of this report for the Children's Hospice Project, case management will be presented within a conceptual framework best described as child and family centered and the term care coordination seems to better describe this service for children with life threatening conditions.

Care coordination is a service commonly found in some of the state level programs discussed in this report, particularly those serving children with special health care needs. For example, care coordination is a component service provided with early intervention programs, developmental disability programs as well as the community based waivers for children. Care coordination is also identified by Children's Hospice International as a key component of the CHI/PACC™ model.

According to the Massachusetts Consortium for Children with Special Health Care Needs, "care coordination is a central, ongoing component of an effective system of care for children and youth with special health care needs and their families." [22] This same concept is widely accepted by the American Academy of Pediatrics based on their support of the medical home concept.[23] The AAP Committee on Children with Disabilities recently concluded that care coordination is an integral component to the efficient management of the multiple complex issues related to caring for children with special health care needs to result in optimal outcomes for children and their families. In addition, based on the needs of children across multiple health and human service systems, care coordination is a process that links children and families to

[21] Committee on Children with Disabilities, Pediatrics, 1999
[22] Care Coordination: Definition and Principles, prepared by the Care Coordination Work Group, Oct 2005
[23] Defined by the AAP, A medical home is an approach to comprehensive primary care, that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.

services and resources. The care coordination of children with complex health care needs is often not provided by the pediatrician based on lack of time and staff.[24]

Care coordination activities may offer benefits to families and to providers. Some specific activities that care coordination can provide in relationship to accessing resources may include but is not limited to the following:

- Assess the individual needs of the child and family
- Develop an individualized plan of care for the child incorporating the multidisciplinary team
- Understand the range of available community resources and public benefits
- Identify, locate and monitor community resources to assist the child and family
- Facilitate access to health and other services that support the needs of the child and family
- Optimize resources that are available to the child, while avoiding duplicative or unnecessary services and costs
- Facilitate effective communication between families and providers
- Assist the family to become more effective advocates for their child's needs

Refer to Appendix G for the *Care Coordination Presentation* provided to the Children's Hospice Project Team related to case management and care coordination.

Conclusions

Based on this extensive review of potential resources for children with life threatening conditions, there appears to be an abundance of possible sources of support available to military families living in the National Capital Area. Further analysis of resources compared to the needs

[24] Gupta, O'Connor and Quezada-Gomex, Pediatrics 2004

assessment could reveal gaps in existing resources for children and families in the military. These gaps will be further evaluated and ultimately incorporated into a new model design as other components of The Childrens' Hospice Project are completed.

A Resource Profile Chart has been developed to identify types of resources relevant to children with life threatening conditions and the general location of these resources. It is important to note that most organizations and programs that house resources for families have specific factors and guidelines that determine a child and family's eligibility for the specific service. The details of these factors are far too many to include in the chart. The purpose of the chart is to be a general reference to identify some possible options and guidance to families seeking resources. See Appendix H for the *Resource Profile Chart*.

At the beginning of this report, the following questions were identified:

- What types of supports are available to children with life threatening condition and their families?
- Where is information about community resources located?
- What is the process for accessing community resource information?
- What are some of the barriers for families in identifying and finding resource information?
- What strategies can be incorporated in a new model design to optimize access to information about community resources?

Finally, in an effort to answer the questions posed at the beginning, please refer to *Resource Overview Analysis* in Appendix I for an overview of the general conclusions relating to Resources as they relate to the various levels (federal, state, military, local) discussed in this report.

Recommendations for Considerations in New Model Design

Education

- Educate families and providers regarding the types of resources that exist and where they may be located
- Educate families of children with life threatening conditions to utilize existing Military Services such as Military One Source and Military Home front
- Educate Military One Source staff on the variety of specific resources that exist for families who have children with life threatening conditions to enhance dissemination of information to families who are seeking community support

Coordination and Facilitation

- Consider care coordination as a means to assist families in accessing existing resources both in the military and private sectors.
- Develop linkages for families with Military One Source to optimize an Information and Referral role they are currently contracted to deliver to active military personnel
- Encourage the collaboration of existing community programs that provide various types of coordination such as public libraries, Infant and Toddler Programs, school programs, Military One Source, etc. that already exist within the military or civilian world.

System Design

- Design information systems to support the dissemination and access to resource information focused on supporting children with life threatening conditions
- Encourage family networking through such chat forums as Military and Specialized Training of Military Parents (STOMP). This type of networking provides families with experience and information on strategies to problem solve system barriers. A parent may

get information to assist them in navigating systems and accessing services to support their children's needs.

- In a new model design, incorporate quality indicators and metrics to measure usage and access to all possible resources that support families. By optimizing the use of resources within the military system, such as Tricare and Military One Source and supplanting resources that families can access outside of the military system, a full spectrum of services appear to be available to support families. This type of quality review may assist the developing model to better identify potential areas for process improvement especially related to the process for accessing the resource and address some of the areas of vulnerability.

Bibliography

Anderson, B., Loughlin, C., Goldberg, E., & Laffel, L. (2001). Comprehensive, family focused outpatient care for very young children living with chronic disease: Lessons from a program in pediatric diabetes. *Children's Services: Social Policy, Research, and Practice, 4*, 235-250.

Balinsky, W., & Marie, J. (2001). A cost benefit & cost effectiveness update. *Caring Magazine*, 16-19.

Betz, C. L. (1999). Collaborative partnerships: Building new programs and services for children. *Journal of Pediatric Nursing, 14,* 279-280.

Betz, C. L., Schultz, A., & Brown, M. (1998). University affiliated programs: A network of nursing resources for children and youth with disabilities. *Journal of Pediatric Nursing, 24*, 594-596.

Burns, M., & Thornam, C. (1993). Broadening the scope of nursing practice: Federal programs for children. *Pediatric Nursing, 19*, 546-552.

Christ, G., Siegel, K., Mesagno, F., & Langosch, D. (1991). A preventive intervention program for bereaved children: Problems of implementation. *American Journal of Orthopsychiatry, 61*, 168-178.

Davies, B., Brenner, P., Orloff, S., Sumner, L., & Worden, W. (2002). Addressing spirituality in pediatric hospice and palliative care. *Journal of Palliative Care, 18*, 59-67.

Douglas, C. (2001). Health insurance programs for children. *Journal of Pediatric Nursing, 16,* 63-65.

Evans, D. (2000). Developing an effective pediatric hospice program. *Home Health*

Care Consultant, 7, 26-28.

Farel, A., & Rounds, K. (1998). Perceptions about the implementation of a statewide service coordination program for young children: Importance of organized context. *Families in Society: The Journal of Contemporary Human Services*, 606-614.

Feinberg, E. (1999). Enlarging the paradigm public-private partnership in the design of a service plan for a young child with special health care needs. *Infants and Young Children, 11,* 11-16.

Feinberg, E., Swartz, K., Zaslavsky, A., Gardner, J., & Walker, D. (2002). Language proficiency and the enrollment of Medicaid-eligible children in publicly funded health insurance programs. *Maternal and Child Health Journal, 6,* 5-18.

Gilmer, M. (2002). Pediatric palliative care: A family-centered model for critical care. *Critical Care Nursing of North America, 14*, 207-214.

Gupta, V., O'Connor, K. &Quezada-Gomez, C. (2005). Care coordination services in pediatric practices. *Pediatrics 2004, 113,* 1517 - 1521.

Halfon, N., & Berkowitz, G. (1993). Development of an integrated case management program for vulnerable children. *Child Welfare, 72*, 18-28.

Holden, E., DeCarolis, G., & Huff, B. (2002). Policy implications of the national evaluation of the comprehensive community mental health services for children and their families programs. *Children's Services: Social Policy, Research, and Practice, 5,* 57-65.

Huffman, L., Koopman, C., Blasey, C., Botcheva, L., Hill, K., Marks, A., et al. (2002). A program evaluation strategy in a community-based behavioral health and education services agency for children and families. *Journal of Applied Behavioral Science, 38,* 191-215.

Hughes, R. C. (1993). Child welfare services for the catastrophically ill newborn: Part I A confusion of responsibility. *Child Welfare, 72.*

Ketelaar, M., & Vermeer, A. (1998). Parental participation in intervention programs for children with cerebral palsy: Review of research. *Topics in Early Childhood Special Education, 18*, 108-118.

Kier-York, J. E., & Harbold, L. A. (2000). Developing a special needs restraint loaner program for transporting medically fragile children. *Journal of Orthopaedic Nursing, 19*.

Kuchler-O'Shea, R., Kritikos, E., & Kahn, J. (1999). Factors influencing attendance of children in an early intervention program. *The Transdisciplinary Journal, 9,* 61-68.

Liben, S., & Goldman, A. (1998). Home care for children with life-threatening illness. *Journal of Palliative Care, 14*, 33-38.

Lin, C. J., & Lave, J. R. (2000). Utilization under children's health insurance programs: Children with vs. without chronic conditions. *Journal of Health & Social Policy, 11*, 1-14.

Melnyk, B. M., & Alpert-Gillis, L. (1998). The COPE program: A strategy to improve outcomes of critically ill young children and their parents. *Pediatric Nursing, 24*, 521-527.

Miles, M. (2003). Parents of children with chronic health problems: Programs of nursing research and their relationship to developmental science. *Parents and Families*, 21247-21277.

Moore, B. (1996). "I count too." *Continuum*, 18-20.

Naar-King, S., Siegel, P. T., & Smyth, M. (2002). Consumer satisfaction with a

collaborative, interdisciplinary health care program for children with special needs. *Children's Services: Social Policy, Research, and Practice, 5*, 189-200.

Naar-King, S., Siegel, P., Smyth, M., & Simpson, P. (2000). A model for evaluating collaborative health care program for children with special needs. *Children's Services: Social Policy, Research, and Practice, 3*, 233-245.

Nabors, L., Ramos, V., & Weist, M. (2001). Use of focus groups as a tool for evaluating programs for children and families. *Journal of Educational and Psychological Consultation, 12,* 243-256.

Parra, M. M., Goldsleger, F., & Chandler, S. (2001). The ventilator-assisted children/home program. *Caring Magazine*, 12-15.

Pelchat, D., Bisson, J., Ricard, N., Perreault, M., & Bouchard, J. (1999). Longitudinal effects of an early family intervention programme on the adaptation of parents and children with a disability. *International Journal of Nursing Studies, 36*, 465-477.

Robinson, C., Jackson, P., & Townsley, R. (2001). Short breaks for families caring for a disabled child with complex health needs. *Child and Family Social Work, 6*, 67-75.

Santarelli, G., Koegel, R. L., Casas, J. M., & Koegel, L. K. (2001). Culturally diverse families participating in behavior therapy parent education programs for children with developmental disabilities. *Journal of Positive Behavior Interventions, 3*.

Siegel, K., Mesagno, F., & Christ, G. (1990). A prevention program for bereaved children. *American Journal of Orthopsychiatry, 60,* 168-175.

Thayer, P. (2001). Spiritual care of children and parents. *Hospice Care for Children, 2*, 172-189.

Unger, D., Park, E., Antal, P., Tressell, P., Rigney, K., DeRasmo, K., et al. (2000). Serving children with special social and emotional needs: A practical approach to evaluating prevention programs in schools and community settings. *Journal of Educational and Psychological Consultation, 11,* 273-296.

VanderPlaat, M., Samson, Y., & Raven, P. (2001). The politics and practice of empowerment evaluation and social interventions: Lessons from the Atlantic community action program for children regional evaluation. *The Canadian Journal of Program Evaluation, 16,* 79-98.

VanLeit, B., & Crowe, T. (2002). Outcomes of an occupational therapy program for mothers of children with disabilities: Impact on satisfaction with time use and occupational performance. *American Journal of Occupational Therapy, 56,* 402-410.

Worchel-Prevatt, F., Heffer, R., Prevatt, B., Miner, J., Young-Saleme, T., Horgan, D., et al. (1998). A school reentry program for chronically ill children. *Journal of School Psychology, 36*, 261-279.

Zwerdling, T., Davies, S., Lazar, L., Crawford, B., Tucker, L., Boughner, A., et al. (2000). Unique aspects of caring for dying children and their families. *American Journal of Hospice & Palliative Care, 17*, 305-311.

Attachments

A. Resource Description Table

B. Review of Military HOME FRONT Web Site Information

C. Military One Source Report

D. Community Resource Table

E. Web Databases Resource Directory

F. Data Flow Diagram

G. Resource Profile Chart

H. Resource Overview Analysis

I. Care Coordination Presentation

Attachment A

Resource Description Table

Category	Program Types	Program Description	Types of Resource Provided
Federal Level*	Social Security Income (SSI)	Supplemental Security Income (SSI) is a Federal income supplement program funded by general tax revenues. It is designed to help aged, blind, and disabled people, who have little or no income. http://www.ssa.gov/notices/supplemental-security-income/	Financial support (cash) to meet basic needs for food, clothing, and shelter.
	Early Periodic Screening and Diagnostic Testing (EPSDT)	The EPSDT program consist of two mutually supportive, operational components: (1) assuring the availability and accessibility of required health care resources; and (2) helping Medicaid recipients and their parents or guardians effectively use these resources. http://www.cms.hhs.gov/medicaid/epsdt/default.asp	The (EPSDT**)** service is Medicaid's comprehensive and preventive child health program for individuals under the age of 21. EPSDT was defined by law as part of the Omnibus Budget Reconciliation Act of 1989 (OBRA 89) legislation and includes periodic screening, vision, dental, and hearing services. In addition, requires that any medically necessary health care service listed at section 1905(a) of the Act be provided to an EPSDT recipient even if the service is not available under the State's Medicaid plan to the rest of the Medicaid population.
Federal/ State administered	Developmental Disabilities (ADD)	The Developmental Disabilities Act requires ADD to ensure that people with developmental disabilities and their families receive the services and supports they need and participate in the planning and designing of those services. The DD Act established eight areas of emphasis for ADD programs; Employment, Education, Child Care, Health, Housing, Transportation, Recreation, and Quality Assurance. ADD meets the requirements of the DD Act through the work of its four programs:	State Councils on Developmental Disability pursue systems change in some aspect of service or support availability, design or delivery that promotes positive and meaningful outcomes for individuals with developmental disabilities and their families. Protection and Advocacy (P & A) systems, one in each state, protect the legal and human rights of individuals with developmental disabilities. P&A strategies include legal, administrative, and other remedies; information and referral; investigation of incidents of abuse and neglect; and education of policy-makers. University Centers for Excellence in Developmental Disabilities (UCEDDs) are components of a university system or are public or

	http://www.acf.dhhs.gov/programs/add/Factsheet.html	not-for-profit entities associated with universities. UCEDDs provide interdisciplinary pre-service preparation of students and fellows, community service activities, and the dissemination of information and research findings. Projects of National Significance (PNS) is a discretionary program providing ADD with the opportunity to focus funds on emerging areas of concern. This program supports local implementation of practical solutions and provides results and information for possible national replication. PNS also supports technical assistance; research regarding emerging disability issues; conferences and special meetings; and the development of Federal and state policy. Additionally, funding is provided for states to create or expand statewide systems change.
Special Education - State Grants Program for Children with Disabilities	This is an entitlement program of the U.S. Department of Education, Office of Special Education Program administered by state and local education agencies to ensure that all children with disabilities receive a free, appropriate public education (FAPE).	States must provide free, appropriate public education (FAPE) to children ages 6 to 17. States may choose to provide services to students' ages 18 - 21. To qualify for federal assistance for ages 3 - 5, states must make FAPE available to all children ages 3 - 5 with disabilities. Services include: • Preplacement evaluation • Re-evaluation at least once every three years • Individualized education program • Appropriate instruction in the least restrictive environment Related and supportive services include: • Audiology • Psychological services • Physical therapy • Occupational therapy • Transportation • Speech pathology • Counseling services

		• Medical services for diagnostic or evaluation purposes • Social work services
Early Intervention Program for Infants and Toddlers with Disabilities	This is an entitlement program administered by education departments, health departments or other local agencies and co-leads, dependent on state where child resides.	The program purpose is to provide a system of comprehensive, multidisciplinary, coordinated services to infants and toddlers age 0 - 3 with disabilities and to their families. Services include: • Multidisciplinary evaluation and assessment • Individualized Family Service Plan • Audiology • Family training • Medical services for diagnostic purposes • Nursing services • Nutrition services • Occupational therapy • Physical therapy • Service coordination • Other early intervention services for example, assistive devices, speech therapy)
Medicaid Programs	The Medicaid Program provides medical benefits to low-income people who have no medical insurance or inadequate medical insurance. States are required to include certain types of individuals or eligibility groups under their Medicaid plans and they may include others. States eligibility groups will be considered one of the following: categorically needy, medically needy, or special groups. *Medicaid At -a-Glance 2003*	Mandatory State Plan Services include: • Inpatient hospital (excludes inpatient institutional mental health) • Outpatient hospital • Laboratory and x-ray • Certified pediatric and family nurse practitioners • Nursing facility services for age 21 and older • EPSDT for under age 21 • Family planning services and supplies • Physician services • Medical and surgical services of a dentist • Home health services for beneficiaries who are entitled to nursing facility services under the state's Medicaid plan

		(intermittent or part-time nursing services provided by home health agency or by a registered nurse when there is no home health agency in the area, home health aides, medical supplies and appliances for use in the home) • Nurse mid-wife services • Pregnancy related services and service for other conditions that might complicate pregnancy • 60 day postpartum pregnancy related services See *Medicaid Services State Plan Chart* for specific types of optional Medicaid State Plan services.
Maternal and Child Health Services Title V of Social Security Act	This is a health program of the U.S. Department of Health and Human Services, Maternal and Child Health Bureau that is administered by the state Maternal and Child Health programs in cooperation with local public health, Medicaid and other public and private providers	The purpose of this program is to provide core public health functions to improve the health of mothers and children. The target population includes children with special health needs, including by not limited to disabilities. Services may include: • Comprehensive health and related services for children with special health care needs • Basic health services (preventive screenings, prenatal and postpartum care, delivery, pediatric care, nutrition, immunization, drugs, lab tests, dental • Enabling services such as transportation, case management, home visiting, translation, services, other services.
Foster Care Adoption Assistance	These programs are administered by state public child welfare agencies or departments of social services to assist states in paying maintenance costs for adopted children with special needs and to prevent inappropriate stays in foster care.	Services include: • Direct cost of foster care maintenance • Placement • Case planning and review • Training for staff, parents, and private agency staff • Maintenance subsidies for dependent child from time of placement for adoption until age 18 or (21) • Training for staff and adoptive parents

	Employment • Vocational Rehab • Supported Employment	These programs are administered by state vocational rehabilitation offices and to prepare persons with disabilities to engage in competitive employment and to create and sustain jobs for disabled individuals who require competitive employment. *Although these services are usually implemented at 21 years of age, they should be considered in transition planning from youth to adult services.	Services include: • Job training, referral, placement, follow up • Surgery, prosthetic and orthotic devices • Assistive devices • Treatment for emotional disorders • Interpreter and reader services • Transportation • Occupational licenses • Tools, equipment, supplies • Counseling • Coordination of services for students transitioning from school to work • Development of employment activities • On-site job coaches • Modification of job/ workplace
	Legal Rights Protection and Advocacy for Individual Rights	This program is administered through state protection and advocacy agencies to enable persons with disabilities to be a part of everyday community life at school, work and home by protecting their legal and human rights	Services include: • Provides information and referral • Seeks to end discrimination against persons with disabilities particularly with respect to fair housing and employment issues
Military	TRICARE	TRICARE covers most health care that is medically necessary. But there are special rules or limits on certain types of care. TRICARE provides various levels of coverage such as TRICARE Standard, TRICARE Extra and TRICARE Prime. TRICARE Standard is the basic TRICARE health care program, offering comprehensive health care coverage, for people not enrolled in TRICARE Prime. Active duty service members must take action to enroll in Prime, and many other beneficiaries choose to	• Funding for specified health care costs as dependent upon type of policy • Case Management under certain conditions • Standard is a fee-for-service plan that gives beneficiaries the option to see any TRICARE-certified/authorized provider (doctor, nurse-practitioner, lab, clinic, etc.). Standard offers the greatest flexibility in choosing a provider, but it will also involve greater out-of-pocket expenses. Beneficiaries may be required to file their own claims. • Standard requires that you satisfy a yearly deductible before TRICARE cost sharing begins, and you will be required to pay

	enroll in Prime also. Standard does not require enrollment.	co-payments or cost shares for outpatient care, medications, and inpatient care. • Established provider network for health care providers • TRICARE Standard helps pay most hospital bills for semi-private rooms, meals (including special diets), diagnostic tests, and treatment. It covers medical supplies such as bandages and syringes. And, it helps pay for covered care at some health care centers other than hospitals. • Prime is TRICARE's managed-care option, similar to a civilian HMO (health maintenance organization).
Exceptional Family Member Program	The Military Services use the term Exceptional Family Member Program (EFMP) to refer to two different functions: a personnel function and a family support function.	The EFMP personnel function: • Is a mandatory program for all active duty service members. • Is standard across all Services. • Identifies family members with special medical and/or educational needs, • Documents the services they require, and • Considers those needs during the personnel assignment process (especially when approving family members for accompanied travel to overseas locations). • Involves the personnel and medical commands and the Department of Defense educational system overseas. The EFMP family support function: Is not mandatory. DoD policy on family centers allows, but does not require, the Military Services to offer family support services to exceptional family members within the Military Services' family support systems. Differs from Service to Service.
Military HOMEFRONT website	"Military HOMEFRONT is the central, trusted, up-to-date source for Service members and families to obtain information about all Quality of Life programs and services." http://www.militaryhomefront.dod.mil/	Information regarding programs available to military families, Leadership and service providers.

	Military One Source	Military *OneSource* is a program administered by Ceridian to assist active military members and their families in locating resources and services to meet any needs they may identify.	The primary role for Military *OneSource* is to provide education and options for potential resource supports.
Disease Specific	Based on specific condition of individual	There are hundreds of organizations that exist that provide information and resources for persons who have a specific disease or condition. These are too numerous to list individually. As an example of some of the possible disease or condition specific organizations, the website for the National Organization of Rare Disorders provides a comprehensive list of conditions, some of which are life threatening or may be a co-existing condition for someone with a life threatening condition. http://www.rarediseases.org/programs/links/library	Programs & Services : The following list represents a "Library Of Links" as outlined on the National Organization of Rare diseases as an example of the types of programs and services related to condition related resources. • NORD's Database of 2,000 Patient Organizations and Government Agencies • NORD Member Organizations (125) • Academic Clinical And/Or Research Centers for Rare Diseases (1) • Cancer Resources (1) • Clinical Trials (3) • Conferences & Presentations (1) • General Health Sites (9) • Genetics For Medical Professionals (2) • Genetics Information (3) • Government Sites (14) • Health Policy Information (1) • Health Privacy Information (3) • International Sites (8) • Laboratory Testing • Medicare/Medicaid Information (8) • National Family Caregivers Month • Newborn Screening (2) • Planning For Children With Special Needs (1) • Resources for People with Disabilities (1) • Umbrella Organizations (23) • Universities/Hospitals (8) • Women's Health (1)

Other Local community resources	Disease Based Foundations Local resources	• Other Sites of Interest (4) http://www.rarediseases.org/programs/links/library The following list represents categories of community resources identified in the National Capital Area. • Associations and Care Organizations • Hospitals and Health Facilities • Hospice • Medical Information Sources • Government Resources • Adaptive Technology • Child Care • Financial Assistance • Medical Providers • Hotlines • Interpreters and Translation Services • Mental Health • Recreation and Camps • Support Groups • Transportation • Respite Care • Utility Assistance Programs • Wish Granting Programs • Special Education Information and Laws • Home Health Care • Durable Medical Equipment and Supplies • Bereavement Services • Self Esteem • Adult Day Care • Hearing/Visually Impaired • Vocational/Rehabilitation Services • Caregiver Resources • Resource Directories

- Case Management Services
- Community Resources
- Pharmacy Programs
- Planning
- Therapeutic Services
- Literature

ATTACHMENT B

	A	B	C	D	E	F
1						
2	**Military HOMEFRONT Site Map Review for topics and relevance to Children with Life Threatening Conditions**					
9	Rating of Relevance High (1) **-cshcn/medical focus child and family, but not elderly** Moderate (2)- Low (3) **is elderly and generically relevant to DoD personnel and situations**					
10	**Site MapTopic Headings**	**Relevance to Population 1=high 2=moderate 3=low**	**Level 3**	**Level 2**	**Level 1**	**Target Audience for Information**
11	Quick Links (External)	0				
12	Military OneSource	1				
13	DoD Severe Disabilities Impact Aid	1		DoD Impact Aid	DoD Impact Aid	Troops and Families
14	Special Needs	1		Education	Education	Troops and Families
15	Child Abuse Risk Factors	1		Child Abuse	Interpersonal Abuse	Troops and Families
16	Reporting Child Abuse	1		Child Abuse	Interpersonal Abuse	Troops and Families
17	Preventing Child Abuse	1		Child Abuse	Interpersonal Abuse	Troops and Families
18	New Parent Support Program	1	Preventing Child Abuse	Child Abuse	Interpersonal Abuse	Troops and Families
19	Never Shake a Baby	1	Preventing Child Abuse	Child Abuse	Interpersonal Abuse	Troops and Families
20	Child Advocates	1		Child Abuse	Interpersonal Abuse	Troops and Families

	A	B	C	D	E	F
21	Medical and Dental	1	Medical and Dental	Medical and Dental	Medical and Dental	Troops and Families
22	Defense Eligibility Enrollment Reporting System	1		Medical and Dental	Medical and Dental	Troops and Families
23	Military Treatment Facility Locator	1		Medical and Dental	Medical and Dental	Troops and Families
24	Navigating Health Care	1		Medical and Dental	Medical and Dental	Troops and Families
25	Exceptional Family Member Program (EFMP)	1			Special Needs/EFMP	Troops and Families
26	Confidentiality	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
27	Army Exceptional Family Member Program	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
28	Army EFMP Coordinators	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
29	Navy Exceptional Family Member Program	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
30	Navy EFMP Coordinators	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
31	USMC Exceptional Family Member Program	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
32	USMC EFMP Coordinators	1	USMC Exceptional Family Member Program	Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
33	Air Force Exceptional Family Member Program	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
34	Air Force Special Needs Officers	1	Air Force Exceptional Family Member Program	Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families

	A	B	C	D	E	F
35	National Guard State Family Programs	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
36	Coast Guard Work Life Programs	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
37	Early Intervention	1		Early Intervention	Education	Troops and Families
38	Eligibility	1		Early Intervention	Education	Troops and Families
39	Military Issues	1		Early Intervention	Education	Troops and Families
40	Contacts	1		Early Intervention	Education	Troops and Families
41	Eligibility	1		Special Education 3-21 years of age	Education	Troops and Families
42	Military Issues	1		Special Education 3-21 years of age	Education	Troops and Families
43	Regulations	1		Special Education 3-21 years of age	Education	Troops and Families
44	Contacts	1		Special Education 3-21 years of age	Education	Troops and Families
45	Program for Persons with Disabilities	1		TRICARE	Medical Care	Troops and Families
46	Contacts	1		TRICARE	Medical Care	Troops and Families
47	Case Management	1		TRICARE	Medical Care	Troops and Families
48	Hospice Care	1		TRICARE	Medical Care	Troops and Families
49	Respite Care	1		TRICARE	Medical Care	Troops and Families
50	Navigating Military Health Care	1		TRICARE	Medical Care	Troops and Families
51	Eligibility	1	Medicaid	Federal Programs	Medical Care	Troops and Families
52	Military Issues	1	Medicaid	Federal Programs	Medical Care	Troops and Families
53	Application Process	1	Medicaid	Federal Programs	Medical Care	Troops and Families

	A	B	C	D	E	F
54	Contacts	1	Medicaid	Federal Programs	Medical Care	Troops and Families
55	Eligibility	1	Title V	Federal Programs	Medical Care	Troops and Families
56	Military Issues	1	Title V	Federal Programs	Medical Care	Troops and Families
57	Application Process	1	Title V	Federal Programs	Medical Care	Troops and Families
58	Contacts	1	Title V	Federal Programs	Medical Care	Troops and Families
59	Family Connections	1		Family Connections	Medical Care	Troops and Families
60	Family Stories	1		Family Stories	Medical Care	Troops and Families
61	EFM Support	1		Family Support	Medical Care	Troops and Families
62	Special Needs Child Care	1		Family Support	Medical Care	Troops and Families
63	Respite Care	1		Family Support	Medical Care	Troops and Families
64	SSD (Social Security Disability)	1	Federal Programs	Financial & Legal Issues	Medical Care	Troops and Families
65	State Resources	1		Resources	Medical Care	Troops and Families
66	FAQs	1		Resources	Medical Care	Troops and Families
67	ToolBox	1		Resources	Medical Care	Troops and Families
68	For Children	2		Child Development Programs	Children and Teens	Troops and Families
69	For Teens	2		Child Development Programs	Children and Teens	Troops and Families
70	Kids Information on Deployment Stuff	2			Deployment	Troops and Families
71	Preschool	2		Education	Education	Troops and Families
72	K-12	2		Education	Education	Troops and Families

	A	B	C	D	E	F
73	Scholarships	2		Education	Education	Troops and Families
74	Children & Youth	2		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
75	Libraries	2		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
76	The Healthy Parenting Initiative	2		Parenting	Parenting	Troops and Families
77	The New Parent Support Program	2		Parenting	Parenting	Troops and Families
78	Techniques for the Fussy Baby	2		Parenting	Parenting	Troops and Families
79	Head Start/Sure Start	2		Head Start/Sure Start	Education	Troops and Families
80	Recreation	2		Family Support	Medical Care	Troops and Families
81	Food Stamps	2	Federal Programs	Financial & Legal Issues	Medical Care	Troops and Families
82	FSSA (Family Subsistence Supplemental Allowance)	2	Federal Programs	Financial & Legal Issues	Medical Care	Troops and Families
83	WIC/WICO (Women, Infants and Children Program)	2	Federal Programs	Financial & Legal Issues	Medical Care	Troops and Families
84	SSI (Supplemental Security Income)	2	Federal Programs	Financial & Legal Issues	Medical Care	Troops and Families
85	EIC (Earned Income Credit)	2	Federal Programs	Financial & Legal Issues	Medical Care	Troops and Families
86	Transition Planning	2			Medical Care	Troops and Families
87	Guardianship	2			Medical Care	Troops and Families
88	What's New	2		Resources	Medical Care	Troops and Families
89	US Army	3				
90	US Marine Corps	3				
91	US Navy	3				
92	US Air Force	3				
93	US Coast Guard	3				
94	National Guard	3				
95	Reserves	3				

	A	B	C	D	E	F
96	Faces of Defense	3				
97	Military.com	3				
98	Militarybenefits.com	3				
99	MilSpouse.org	3				
100	Pre-Paid Phone Cards	3			Special offers	
101	Calendar	3		Calendar	Calendar	Troops and Families
102	Special Observances	3		Calendar	Calendar	Troops and Families
103	Army and Air Force Exchange Service	3			Commissaries and Exchanges	Troops and Families
104	Defense Commissary Agency	3			Commissaries and Exchanges	Troops and Families
105	Marine Corps Exchange	3			Commissaries and Exchanges	Troops and Families
106	Navy Exchange	3			Commissaries and Exchanges	Troops and Families
107	Deployment Preparation	3			Deployment	Troops and Families
108	DeploymentLink	3			Deployment	Troops and Families
109	During Deployment	3			Deployment	Troops and Families
110	Return and Reunion	3			Deployment	Troops and Families
111	Post-Deployment	3			Deployment	Troops and Families
112	FAQs	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
113	Terms & Acronyms	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
114	DoD Supplemental Impact Aid	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
115	Laws, Regulations & Policies	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
116	Funding History & Forms	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
117	Additional Resources	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
118	Federal Education Programs	3		DoD Impact Aid	DoD Impact Aid	Troops and Families

	A	B	C	D	E	F
119	DoD Education Programs & Resources	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
120	Impact Aid	3		Education	Education	Troops and Families
121	Veterans Military Education and Training	3		Education	Education	Troops and Families
122	Voluntary Education	3		Education	Education	Troops and Families
123	General Information	3		Eldercare	Eldercare	Troops and Families
124	Medicaid	3		Eldercare	Eldercare	Troops and Families
125	Medicare	3		Eldercare	Eldercare	Troops and Families
126	Resources	3		Eldercare	Eldercare	Troops and Families
127	Social Security Administration	3		Eldercare	Eldercare	Troops and Families
128	TRICARE for Life	3		Eldercare	Eldercare	Troops and Families
129	Casualty Assistance	3		Emergencies and Disasters	Emergencies and Disasters	Troops and Families
130	Emergency Assistance	3		Emergencies and Disasters	Emergencies and Disasters	Troops and Families
131	DoD Resources	3		Jobs	Employment	Troops and Families
132	Government Resources	3		Jobs	Employment	Troops and Families
133	Service Resources	3		Jobs	Employment	Troops and Families
134	Other Resources	3		Jobs	Employment	Troops and Families
135	Family Member Employment	3			Employment	Troops and Families
136	Guard and Reserves	3			Guard and Reserves	Troops and Families
137	Military Housing	3		Military Housing	Housing	Troops and Families
138	Renting and Buying	3		Military Housing	Housing	Troops and Families

	A	B	C	D	E	F
139	What is FAP?	3			Interpersonal Abuse	Troops and Families
140	Domestic Abuse	3			Interpersonal Abuse	Troops and Families
141	Domestic Abuse Risk Factors	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
142	Victim Advocates	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
143	Reporting Domestic Abuse	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
144	Civilian and Military Protective Orders	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
145	Transitional Compensation Program	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
146	Preventing Domestic Abuse	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
147	Defense Task Force on Domestic Violence	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
148	Resources	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
149	Transitional Compensation Program	3			Interpersonal Abuse	Troops and Families
150	Resources	3			Interpersonal Abuse	Troops and Families
151	Legal Matters	3	Legal Matters	Legal Matters	Legal Matters	Troops and Families
152	Military Severely Injured	3		Military Severely Injured	Military Severely Injured	Troops and Families
153	Business Programs	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
154	Fitness & Sports	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
155	Funding Standard	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
156	Glossary	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families

	A	B	C	D	E	F
157	History	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
158	Leisure Travel	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
159	Links	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
160	Patronage	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
161	Recreation	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
162	Single Service Member	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
163	What's New?	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
164	Defense Finance and Accounting Service	3		Pay and Benefits	Pay and Benefits	Troops and Families
165	OSD Military Compensation Site	3		Pay and Benefits	Pay and Benefits	Troops and Families
166	Hot Information Sites	3		Personal Finances	Personal Finances	Troops and Families
167	Don't Get Scammed	3		Personal Finances	Personal Finances	Troops and Families
168	Financial Readiness Programs	3		Personal Finances	Personal Finances	Troops and Families
169	Points of Contact	3		Networking / Partnerships	Networking / Partnerships	Troops and Families
170	Planning	3			Relocation	Troops and Families
171	Plan My Move	3		Planning	Relocation	Troops and Families
172	Plan My Budget	3		Planning	Relocation	Troops and Families
173	Plan My Housing	3		Planning	Relocation	Troops and Families

	A	B	C	D	E	F
174	Plan My Travel	3		Planning	Relocation	Troops and Families
175	Plan My Timeline	3		Planning	Relocation	Troops and Families
176	Hints and Tip Sheets	3		Relocation	Relocation	Troops and Families
177	Career Education	3		Children over 21	Education	Troops and Families
178	Vocational Rehabilitation	3		Children over 21	Education	Troops and Families
179	Housing Needs	3		Children over 21	Education	Troops and Families
180	Community Living	3		Children over 21	Education	Troops and Families
181	Section 811	3		Children over 21	Education	Troops and Families
182	Loans for Accommodations	3		Children over 21	Education	Troops and Families
183	Age Limitations	3		Children over 21	Education	Troops and Families
184	Medicare	3		Federal Programs	Medical Care	Troops and Families
185	Services & Benefits	3	Medicare	Federal Programs	Medical Care	Troops and Families
186	Eligibility	3	Medicare	Federal Programs	Medical Care	Troops and Families
187	Application Process	3	Medicare	Federal Programs	Medical Care	Troops and Families
188	Contacts	3	Medicare	Federal Programs	Medical Care	Troops and Families
189	Estate Plans	3		Financial Planning	Medical Care	Troops and Families
190	Tax Benefits	3		Financial Planning	Medical Care	Troops and Families
191	IRS Assistance	3		Financial Planning	Medical Care	Troops and Families
192	Resources	3		Financial Planning	Medical Care	Troops and Families
193	Monthly Expenses Calculator	3		Financial Planning	Medical Care	Troops and Families

	A	B	C	D	E	F
194	Transition Assistance	3			Transition Assistance	Troops and Families
195	United In Memory/UIM	3			United In Memory/UIM	Troops and Families
196	Pentagon Memorial	3			United In Memory/UIM	Troops and Families
197	Pentagon Renovation and Construction	3			United In Memory/UIM	Troops and Families
198	Operation Solace	3			United In Memory/UIM	Troops and Families
199	Helping Families Cope	3			United In Memory/UIM	Troops and Families
200	Defend America	3			United In Memory/UIM	Troops and Families
201	PFAC After Action Report	3			United In Memory/UIM	Troops and Families
202	Benefactors	3			United In Memory/UIM	Troops and Families
203	Links	3			United In Memory/UIM	Troops and Families

Attachment C

Military *OneSource*

Background Information

On June 17, 2004 an onsite visit was made to the Ceridian office in Plymouth Meeting, Pennsylvania for the purpose of understanding the Military *OneSource* Program available to active military personnel. Military *OneSource* is a program administered by Ceridian to assist active military members and their families in locating resources and services to meet any needs they may identify. The primary role for Military *OneSource* is to provide education and options for potential resource supports.

The site visit included spending the day with Ronald White, Director for Military Program Management and Dan Lafferty, Clinical Supervisor for the program. Mr. White has an extensive background in social work as well as international experience related to information and referral supports. Mr. Lafferty is a licensed social worker with certification as an Employee Assistance Professional with military experience in the Air Force. Both have expert experience in the area of employee benefits.

In addition to providing services for the military, Ceridian serves over 10,000 organizations internationally, which translates to over 10 million employees. This Employee Assistance Program (EAP) benefit has been phased in to the various branches of the military over the past four years and is currently available to the Army, Marine Corps, Air Force and Navy. Mr. White estimates that 2.6 million individuals in the military have access to this benefit. Extensive and active marketing campaigns have been

implemented to ensure awareness of the service as well as information about its use. Utilization data is tracked and sorted by service branch and reviewed to identify areas for further marketing opportunities for Ceridian.

During the visit, Ceridian personnel emphasize the company's commitment to meeting the needs of the population as it operates an extensive quality assurance program that is evident throughout the facility and through interviews with various personnel.

In an effort to build a collaborative relationship between Military *OneSource* and the project team, Carol Marsiglia led a discussion regarding the *m*Care Project. Juli Lausch prepared an extensive list of questions to be addressed throughout the tour and again at the end of the day. Deona Howard also attended the day. The discussion included an overall description of the project and phases for development of a model of care for children of military families who have life threatening conditions. In addition, use of community and military resources was emphasized to identify areas of potential interface between Ceridian services and needs of the population. Mr. White indicated a willingness to support the project through the use of Ceridian services. The role of the company as it relates to Military *OneSource* is that of referral and education. Therefore, it is important to note that accessing services identified by Ceridian is the responsibility of the military personnel seeking assistance and beyond the scope of service provided by Ceridian.

There are three Ceridian service centers in the United States that serve the military at home and abroad. These offices are located in Plymouth Meeting, PA, Minneapolis, MN and Miami, FL. The Plymouth Meeting and Minneapolis locations are

described as mirror images of each other with Miami specializing in multilingual and multicultural services. All locations have access to a translation service.

Tour of Service Center

Information Technology and Telecommunications

Jo-Anne Mullen, Director and Jerry McDonnell, who are ultimately responsible for the overall security of the data system, presented an overview of the Information Technology and Telecommunications Center. A predictive algorithm is used to process calls to ensure efficiency in answering call volume. The time standard set to respond to a call is 20 seconds with no automated answering system used. The calls are answered by a trained triage specialist who then forwards the calls to the appropriate content specialist. There are over 200 phone numbers used to access the organization's services. International access is available and the organization accepts collect calls.

Mullen and McDonnell described an extensive disaster plan and reported that it is tested regularly. They stated that in the event of a disaster, all calls can be moved to an alternate center through "5 key strokes" and that this is a transparent process to the caller. As part of the disaster plan, a redundancy plan is in effect. All data is replicated at the Minneapolis center allowing consultants at other centers to access all data information necessary for business continuity, as well as storage of backup at an alternate location in Louisville, Kentucky. Backups occur multiple times throughout the day.

In addition to telephone based communications, the service is web based and operates on multiple servers that are reportedly able to handle extremely high volume loads with no evidence of performance problems. Utilization trends are reported to vary

with the Army population, in that 70 % of requests are received via Internet with 30% via telephone. The other military branches are reported to be approximately 80% Internet with 20% telephone requests.

Mr. White indicates that they anticipate greater Army telephone usage over time, similar to other organizational patterns. Generally, utilization reporting is based on service type, location, and demographics such as military grade and family member using the service. Custom reports can be designed and provided upon request.

Fulfillment Center

The Fulfillment Center houses educational materials and publications that are provided to the Ceridian consultants to meet the needs of the individuals making information requests. Information distributed has been developed by or cited from experts in a particular content area. For military specific content, such as items that can be sent overseas, military personnel review the information. For more generic topics, such as coping with stress, only information validated by experts in the field is used. Some publications can be reproduced within the Fulfillment Center and some are purchased for distribution.

Service Delivery/ Research

Masters level consultants handle all calls for Military *OneSouce* and the staff is configured into teams. Clinical Supervisors are responsible for Consultant Teams and are to be notified of all situations defined as significant. Examples of these would include such issues as domestic, child or elder abuse, as well as concerns that have legal implications. The Clinical Supervisor is then responsible to ensure that all actions and resources have been provided to the requestor to address the issue. In addition, the

Clinical Supervisor is responsible for reviewing two cases per month for each Consultant on their team as a part of the quality assurance process for services.

Call information such as demographics and requests are documented in the Case Management System, which is a custom developed software system used by the Ceridian staff. The software is an integrated system that communicates with scheduling for tracking purposes, reporting for utilization and communication with Fulfillment area as well as with other members of the service delivery team. During normal business hours, calls are triaged and assigned to Consultant Specialists or Consultant Generalists, dependant upon caller needs. During non-business hours, calls are handled by Consultant Generalists and assigned as necessary to specialists. Calls are accepted 24 hours per day, 7 days per week and 365 days per year. Consultant Specialists are available in the area of adoption, childcare, disability, education and international resources. All other topics are handled by Consultant Generalists. Consultants use an internal database of existing resource information or they send a request to a researcher for more specific information. The researcher also has access to an internal database of resources, as well as an Internet capability search. The researcher can utilize multiple strategies to access information requests. All information for contact is validated by the researcher prior to submission back to the consultant for distribution to the requester. For health specific information, researchers are expected to use web sites that are credible based on their URL including "edu", "gov" or "org".

The service center itself is a rather large area of individually divided workspaces separated by low level partitions, each equipped with a desk computer and telephone. The area is remarkably quiet despite the constant communication between requesters of

information and Consultants. Each Consultant wears earphones and therefore no telephone tones are overheard in the work areas.

The service delivery system is currently in the process for accreditation by the Commission on Accreditation.

Quality Management

An emphasis on quality is evident throughout the organization as demonstrated by real time data and quality targets posted throughout the service center. These quality targets include answered calls, average hold time and calls abandoned. Goals that are below target are shown in red while on target goals are green. Diane Opere is a manager in Quality Services. She explained that user feedback is extremely important to the organization and is measured through various modes. There is an Interactive Voice Audit Survey and an online survey offered to all customers. The Interactive Voice Audit System allows the customer to answer survey questions in an anonymous way. The online survey is sent 1 week following intervention by Military *OneSource*. Overall return rates are reported at 25% for telephone audit and 28% electronically. Under certain circumstances, referral options are tagged "do not use" based on responses from consumers. Customer feedback reports are submitted to clinical supervisors on a monthly basis. Ceridian reports that they are currently working with the Military Research Center at Purdue relative to outcome measures. The company is currently attempting to demonstrate outcomes such as time saved and decreased stress in seeking resource information. Next generation outcome work will be geared toward measurement of military readiness and retention. Ceridian is reportedly considered a

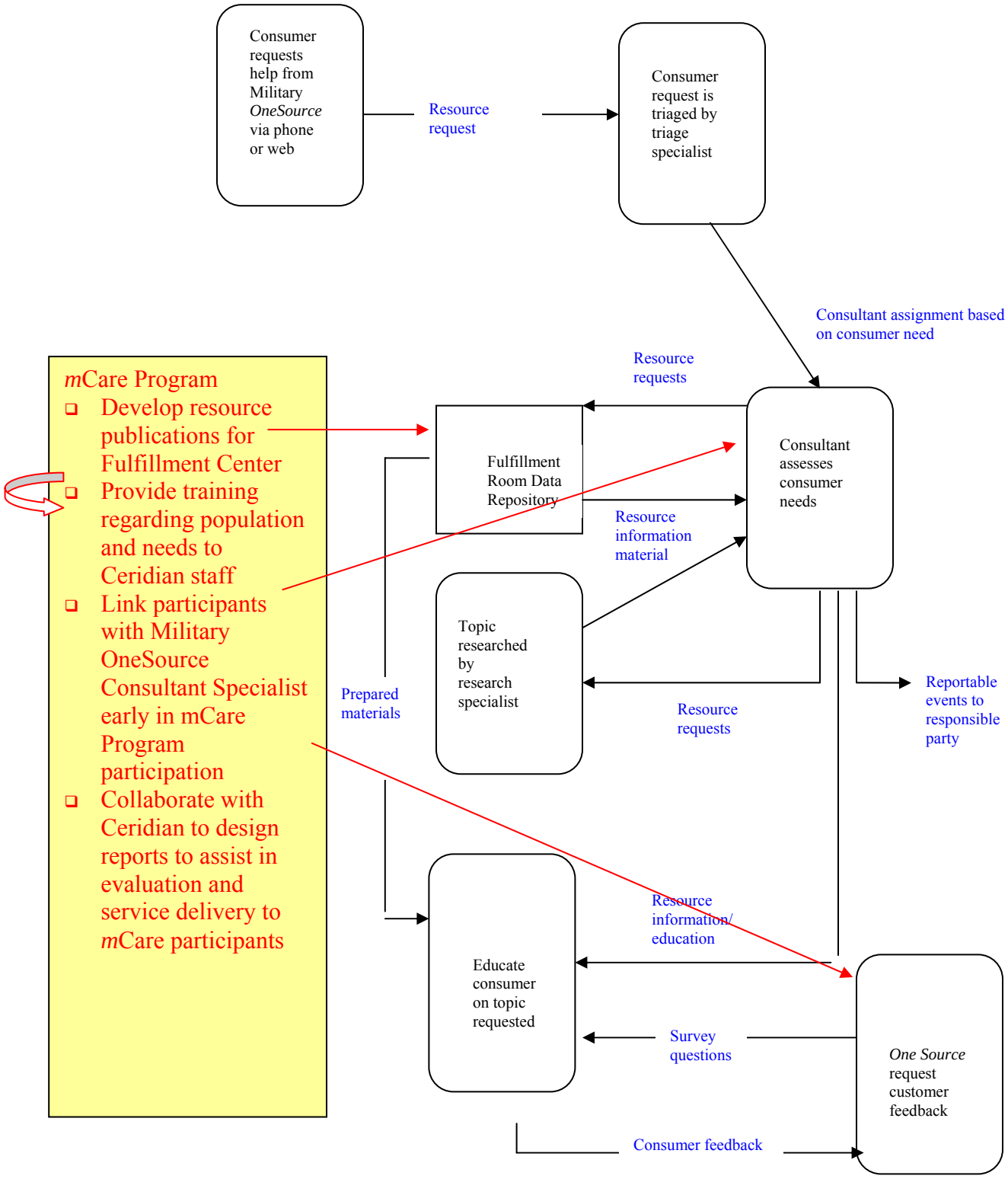
business associate as it relates to the Health Information Accountability and Portability Act (HIPAA).

Recommendations

- Incorporate use of Military *OneSource* Program in future program model to support access to military and community resources as well as general educational information on family related topics.
- Identify information topics that apply to children with life threatening conditions for inclusion in Military *OneSource* databases.
- Collaborate with Ceridian to incorporate publications that target the needs of children with life threatening conditions, specifically including CHI publications relating to palliative care.
- Identify additional resource linkages to Military *OneSource* that are specific to the *m*Care population.
- Offer training for Military *OneSource* Supervisors, Consultants (general and specialist) and researchers regarding *m*Care population.
- Consider reporting needs for *m*Care population and collaborate with Ceridian to submit reports for targeted population.
- Incorporate Health on the Net Code Guidelines related to the distribution of medical and health specific information to ensure credibility and quality.
- Identify any issues related to HIPAA regarding the distribution of resource or health information as it relates to model/program design.

- Educate families participating in *m*Care on the benefits of telephonic mode to promote comprehensive response to the needs request.
- Address the gap regarding accessing services as it relates to the education and resource information role of Military *OneSource* verses more intensive care coordination.
- Develop a means to measure outcomes related to the use of Ceridian services with the *m*Care population.

Data Flow Diagram
Military *OneSource* Process for Resource Information Requests



ATTACHMENT D

ID #	RESOURCE NAME	NEW CATEGORY
25	Life Link	Adaptive Technology
60	Adaptive Mall	Adaptive Technology
62	Ablenet	Adaptive Technology
[illegible]	Crestwood Communication Aids	Adaptive Technology
[illegible]	Direct Link, Emergency Monitoring System	Adaptive Technology
[illegible]5	Medic Alert	Adaptive Technology
115	Enabling Devices	Adaptive Technology
116	Integrations	Adaptive Technology
117	Sport Time	Adaptive Technology
118	Flaghouse	Adaptive Technology
156	Dakota Link	Adaptive Technology
157	Horcher Lifting Systems	Adaptive Technology
162	Abilitations	Adaptive Technology
163	Southpaw Enterprises	Adaptive Technology
169	Health Science	Adaptive Technology
170	Dynavox	Adaptive Technology
171	Maryland Accessible Telecommunications Program	Adaptive Technology
228	ATLFA – Virginia	Adaptive Technology
411	Assistech	Adaptive Technology
413	AVRS Inc.	Adaptive Technology
414	Computer Prompting and Captioning	Adaptive Technology
416	Future Home	Adaptive Technology
420	Assisted Access and NFSS Communication	Adaptive Technology
424	RESNA – Rehab. Engineering and Assistive Technology	Adaptive Technology
426	Office of Volunteers for Medical Engineering	Adaptive Technology
428	Wheelchair Society	Adaptive Technology
486	Montgomery College Disability Support	Adaptive Technology
[illegible]	Montgomery College Disability Support – Takoma Park Campus	Adaptive Technology
488	Montgomery College Disability Support – Germantown Campus	Adaptive Technology
905	SHARE Network	Adaptive Technology
430	Asbury Methodist Adult Day Care	Adult Day Care
431	Misler Adult Day Center	Adult Day Care
434	Support Center – Rockville	Adult Day Care
439	Bethesda Fellowship House	Adult Day Care
500	The League for People with Disabilities – Fehsenfield Medical Day Program	Adult Day Care
501	The League for People with Disabilities – Adult Day Services for Seniors	Adult Day Care
432	Randolph Hills Nursing and Adult Day Care	Adult Day Care / Nursing Home
95	Charlestown	Assisted Living
261	Tranquillity at Fredericktowne	Assisted Living
607	Automatic Senior Assisted Living	Assisted Living
435	Winter Growth	Assisted Living / Adult Day Care
96	Renaissance Gardens-rehabilitation care unit	Assisted Living / Health Facility
69	Bello Machre	Associations and Care Organizations
70	Bello Machre - Community Living	Associations and Care Organizations
71	Bello Machre - Family Living	Associations and Care Organizations
72	Bello Machre - Support Services	Associations and Care Organizations
82	The Magic Foundation	Associations and Care Organizations
98	Epilepsy Foundation	Associations and Care Organizations
99	Abilities Network	Associations and Care Organizations
2[illegible]	ARC of Anne Arundel County	Associations and Care Organizations
[illegible]	CHADD	Associations and Care Organizations
[illegible]1	Spina Bifida Association of America	Associations and Care Organizations
213	Birthright International	Associations and Care Organizations
214	Learning Disabilities Association of America	Associations and Care Organizations
216	The ARC of Frederick County – Support services	Associations and Care Organizations
219	United Way of Frederick County	Associations and Care Organizations

220	American Red Cross – Frederick County	Associations and Care Organizations
226	Salvation Army – Frederick County	Associations and Care Organizations
231	Alzheimer's Association – Frederick	Associations and Care Organizations
2[illegible]	The Arthritis Foundation – Western Maryland Chapter	Associations and Care Organizations
[illegible]	Care Net Pregnancy Center	Associations and Care Organizations
[illegible]42	Cystic Fibrosis Foundation	Associations and Care Organizations
249	Yes I Can International	Associations and Care Organizations
259	The Leukemia & Lymphoma Society	Associations and Care Organizations
305	Allergy/Asthma Network – Mothers of Asthmatics Inc.	Associations and Care Organizations
307	Asthma and Allergy Foundation	Associations and Care Organizations
311	Autism Society of America	Associations and Care Organizations
316	Bear Necessities Pediatric Cancer Foundation	Associations and Care Organizations
317	The Brain Injury Association of MD	Associations and Care Organizations
327	Maryland Lupus Foundation –	Associations and Care Organizations
329	Sickle Cell Association of America	Associations and Care Organizations
337	Chesapeake Potomac Spina Bifida Association	Associations and Care Organizations
354	Hospice Network of Maryland	Associations and Care Organizations
356	National Children's Cancer Society	Associations and Care Organizations
380	United Cerebral Palsy – National Headquarters	Associations and Care Organizations
381	UCP of Central Maryland- No Boundaries Assistive Technology Center	Associations and Care Organizations
382	UCP Central Maryland – Central MD Headquarters	Associations and Care Organizations
386	United Cerebral Palsy of Central Maryland – In Home Support – Central	Associations and Care Organizations
394	Americans for Better Care of the Dying	Associations and Care Organizations
415	American Brain Tumor Association	Associations and Care Organizations
[illegible]	Community Services for Autistic Adults and Children	Associations and Care Organizations
[illegible]0	ARC of Montgomery County – Children's Services	Associations and Care Organizations
421	ARC of Montgomery County Family and Community Resources	Associations and Care Organizations
428	ARC of Montgomery County	Associations and Care Organizations
441	Easter Seals Society for Disabled Children and Adults	Associations and Care Organizations
444	Jewish Social Services Agency	Associations and Care Organizations
465	Kennedy Institute	Associations and Care Organizations
473	UCP of Prince George's & Montgomery Co.	Associations and Care Organizations
481	Alexander Graham Bell Association for the Deaf	Associations and Care Organizations
[illegible]	American Speech, Language & Hearing Association	Associations and Care Organizations
[illegible]	Candlelighters – Childhood Cancer Foundation	Associations and Care Organizations
	Believe in Tomorrow – National Children's Foundation	Associations and Care Organizations
	CANCERcare	Associations and Care Organizations
	National Association of Hospitality Houses	Associations and Care Organizations
	National Multiple Sclerosis Society (Headquarters)	Associations and Care Organizations
	Hospice Foundation of America	Associations and Care Organizations
	Super Sibs	Associations and Care Organizations
	National Hospice and Palliative Care Organization	Associations and Care Organizations
	Hospice Education Institute	Associations and Care Organizations
	Association for the Support of Children with Cancer	Associations and Care Organizations
	Muscular Dystrophy Association	Associations and Care Organizations
	Muscular Dystrophy Family Foundation	Associations and Care Organizations
	Parent Project Muscular Dystrophy	Associations and Care Organizations
	Cystic Fibrosis Research, Inc.	Associations and Care Organizations
	Families of Spinal Muscular Atrophy	Associations and Care Organizations
	SMA Support	Associations and Care Organizations

774	Prader-Willi Syndrome Association	Associations and Care Organizations
775	National Spinal Cord Injury Association	Associations and Care Organizations
790	National Fragile X Foundation	Associations and Care Organizations
800	American Spinal Injury Association	Associations and Care Organizations
82[illegible]	The Wellness Community	Associations and Care Organizations
[illegible]	American Association on Mental Retardation	Associations and Care Organizations
[illegible]29	SEEC	Associations and Care Organizations
830	Richcroft Inc.	Associations and Care Organizations
831	Multiple Sclerosis Society - Maryland	Associations and Care Organizations
832	Changing People's Lives (CPL)	Associations and Care Organizations
833	Alliance Inc.	Associations and Care Organizations
834	Lt. Joseph P. Kennedy Institute	Associations and Care Organizations
835	Center for Social Change Inc.	Associations and Care Organizations
836	Community Living Inc.	Associations and Care Organizations
843	Center for Community Integration	Associations and Care Organizations
850	ALSA (ALS Association)	Associations and Care Organizations
855	Hospice Patients Alliance	Associations and Care Organizations
858	Brain Tumor Society	Associations and Care Organizations
859	Children's Brain Tumor Foundation	Associations and Care Organizations
860	Childhood Leukemia Foundation	Associations and Care Organizations
863	Pediatric Brain Tumor Foundation	Associations and Care Organizations
865	American Cancer Society	Associations and Care Organizations
866	American Chronic Pain Association	Associations and Care Organizations
884	The Multiple Sclerosis Association of America	Associations and Care Organizations
899	MSF – Multiple Sclerosis Foundation	Associations and Care Organizations
217	The ARC of Frederick County – Service Coordination	Associations and Care Organizations / Case Management Services
894	National Cystic Fibrosis Awareness Committee	Associations and Care Organizations / Community Resource
765	National Organization for Rare Disorders	Associations and Care Organizations / Medical Information Sources
[illegible]	Madison's Foundation	Associations and Care Organizations / Medical Information Sources
[illegible]6	Children's Hospice International	Associations and Care Organizations / Resource Directories
801	World Association of Physically Disabled	Associations and Care Organizations / Resource Directories
907	Joni and Friends	Associations and Care Organizations / Resource Directories
387	United Cerebral Palsy of Central Maryland - Respite Care	Associations and Care Organizations / Respite Care
739	Starlight Starbright Children's Foundation	Associations and Care Organizations / Wish Granting Programs
722	National Family Caregivers Association	Associations and Care Organizations/ Caregiver Resources
802	MAAP Services for Autism and Asperger Spectrum	Associations and Care Organizations/ Medical Information Sources
79	Hospice of the Chesapeake – Spiritual and Bereavement Care Center	Bereavement Services
239	Healing Hearts for Bereaved Parents	Bereavement Services
333	KIDSAID	Bereavement Services
455	The Compassionate Friends	Bereavement Services
578	Griefnet.org	Bereavement Services
585	St. Agnes - Bereavement Services	Bereavement Services
649	Stella Maris, Center for Grief and Loss	Bereavement Services
856	Dougy Center for Grieving Children and Families	Bereavement Services
857	Beyond Indigo	Bereavement Services
862	Crisis, Grief and Healing	Bereavement Services
875	Comfort Zone Camp	Bereavement Services
356	TAPS - Tragedy Assistance Program for Survivors, Inc.	Bereavement Services
337	Centering Corporation	Bereavement Services
[illegible]	Wendt Center for Loss and Healing	Bereavement Services
[illegible]0	Initiative for Pediatric Palliative Care	Bereavement Services / Community Resources
361	Compassion Books	Bereavement Services / Literature
389	When Children Die: Improving Palliative and End-of Life Care for Children	Bereavement Services / Literature
223	Exceptional Parent	Caregiver Resource / Resource Directories
27	The Family Tree	Caregiver Resources

54	Caring Communities	Caregiver Resources
208	Family Resource Center	Caregiver Resources
210	YWCA West County Family Support	Caregiver Resources
246	Families Plus	Caregiver Resources
2[illegible]	Parent's Place of Maryland	Caregiver Resources
[illegible]	Family Services Agency	Caregiver Resources
[illegible]70	Family Caregiver Alliance	Caregiver Resources
771	Family Voices	Caregiver Resources
809	Strength for Caring	Caregiver Resources
810	Family Partnership of Frederick County	Caregiver Resources
811	Friends of the Family	Caregiver Resources
812	Adelphi/Langley Park Family Support Center	Caregiver Resources
813	Families Foremost Center	Caregiver Resources
199	Department for Family Support Services (Kennedy Krieger)	Caregiver Resources / Case Management Services
804	Matrix Parent Network and Resource Center	Caregiver Resources / Resource Directories
878	Baltimore Health Care Access Inc.	Case Management Services / Resource Directories
309	Health Services for Children with Special Needs	Case Management Services / Respite Care
237	Child Care Choices – Assistance in Locating Childcare	Child Care
442	ARC of Montgomery County – Family and Infant Child Care Center	Child Care
444	ARC of Montgomery County – Child Care Center – Silver Spring	Child Care
445	Locate Child Care	Child Care
767	www.student-sitters.com	Childcare
28	Turnaround Inc.	Community Resources
206	Frederick Community Action Agency	Community Resources
212	Benefits Information Source	Community Resources
222	Gale Houses Inc.	Community Resources
2[illegible]	YMCA – Frederick County	Community Resources
[illegible]	Advocates for Homeless Families	Community Resources
[illegible]2	Frederick Arts Council	Community Resources
235	Seton Center	Community Resources
245	Frederick County Cooperative Extension	Community Resources
247	Goodwill Industries	Community Resources
250	Heartly House	Community Resources
252	Historical Society of Frederick County	Community Resources
258	Legal Aid Bureau	Community Resources
260	Literacy Council of Frederick County	Community Resources
266	Independence Now	Community Resources
300	MD Association of Resources for Families and Youth	Community Resources
318	Learning Services Corporation	Community Resources
320	Autism Outreach Inc.	Community Resources
325	Coalition to End Lead Poisoning	Community Resources
391	Shepherds Table	Community Resources
392	Laurel Advocacy and Referral Services	Community Resources
395	Catholic Charities of the Archdiocese of Baltimore	Community Resources
396	Bethesda Cares Inc.	Community Resources
421	Maryland Disabilities Forum	Community Resources
447	Child Welfare League of America	Community Resources
448	Children's Defense Fund	Community Resources
451	Dept. of Neighborhood & Community Services	Community Resources
452	Adventist Community Services	Community Resources
4[illegible]	C-4 Clothes Closet	Community Resources
[illegible]	Interfaith Services	Community Resources
472	Florence Crittendorn Services of Greater Washington	Community Resources
485	Jewish Council for Aging	Community Resources
57	Creative Options	Community Resources
108	Partners in Care	Community Resources
109	Big Brother / Big Sister of Central Maryland	Community Resources

113	Maryland Disability Law Center	Community Resources
877	EFM Connections	Community Resources / Caregiver Resources / Case Mgt. Services
243	Frederick County Developmental Center	Community Resources / Government Resources
[illegible]	Transplant Resource Center of Maryland	Community Resources / Medical Information Sources
[illegible]	The Special Needs Network	Community Resources / Planning
908	Respite Resources & Information - Virginia Commonwealth University	Community Resources / Respite/ Resource Directories
597	Making Choices for Independent Living	Community Resources / Vocational/Rehabilitation Services
410	Apria	Durable Medical Equipment
39	CPR Medical	Durable Medical Equipment & Supplies
66	Hard Manufacturing	Durable Medical Equipment & Supplies
67	Vail – Enclosed Beds	Durable Medical Equipment & Supplies
104	Mid Atlantic Healthcare	Durable Medical Equipment & Supplies
112	DS Medical	Durable Medical Equipment & Supplies
114	Transtracheal Systems	Durable Medical Equipment & Supplies
119	Quantum Rehabilitation	Durable Medical Equipment & Supplies
120	Home Mediserve	Durable Medical Equipment & Supplies
154	Advanced Respiratory	Durable Medical Equipment & Supplies
155	Medirents	Durable Medical Equipment & Supplies
159	Roberts Home Medical	Durable Medical Equipment & Supplies
164	LEVO	Durable Medical Equipment & Supplies
165	Chesapeake Rehab	Durable Medical Equipment & Supplies
166	Home Delivery of Incontinent Supplies	Durable Medical Equipment & Supplies
167	ROHO	Durable Medical Equipment & Supplies
425	Spectrum Medical	Durable Medical Equipment & Supplies
83	MAMSI	Financial Assistance
84	Jill Fox Fund	Financial Assistance
85	Digital Federal Credit Union	Financial Assistance
[illegible]	Assistive Technology Guaranteed Loan Program	Financial Assistance
[illegible]	Disabled Children's Relief Fund	Financial Assistance
[illegible]	Vision USA	Financial Assistance
201	REACH	Financial Assistance
335	Kidney Disease Program of Maryland	Financial Assistance
336	American Kidney Fund	Financial Assistance
339	Foundation of Dentistry for the Handicapped – Donated Dental Services Program	Financial Assistance
347	Children's Organ Transplant Association	Financial Assistance
456	Clayton Dabney Foundation for Kids	Financial Assistance
511	MCHP	Financial Assistance
525	Bou Tem Sci – Charity Fund	Financial Assistance
546	Medical Care for Children Partnership / Catholic Charities	Financial Assistance
547	Justin Scott Foster Foundation	Financial Assistance
569	Kelly Anne Dolan Memorial Fund	Financial Assistance
594	Jeremy Foundation	Financial Assistance
601	Lungs for Life Foundation	Financial Assistance
669	Challenged America	Financial Assistance
696	Alexander G. Bell Association for the Deaf – Grant for School age children	Financial Assistance
697	Alexander G. Bell Association for the Deaf – Grant for Arts and Sciences	Financial Assistance
698	Alexander G. Bell Association for the Deaf – College Scholarship	Financial Assistance
[illegible]	AMBUCS – Therapeutic Tricycles for Disabled Children	Financial Assistance
[illegible]	Delta Gamma Memorial Scholarship	Financial Assistance
[illegible]	Ferdinand Torres Scholarship	Financial Assistance
702	Karen D. Carsel Memorial Scholarship	Financial Assistance
703	R.L. Gilette Scholarship	Financial Assistance
704	Rudolf Dillman Memorial Scholarship	Financial Assistance
705	Assistive Technology Fund by the Association of Blind Citizens	Financial Assistance

706	Reggie Johnson Memorial Scholarship-Association of Blind Citizens	Financial Assistance
707	Christian Record Services Scholarships	Financial Assistance
[illegible]	Casey Martin Award and Non-Profit Grant Award	Financial Assistance
[illegible]	Billy Barty Foundation Scholarship	Financial Assistance
[illegible]0	Cystic Fibrosis Scholarship Foundation	Financial Assistance
712	Minnie Pearl Foundation Scholarship	Financial Assistance
713	Brighter Tomorrow Grant	Financial Assistance
823	PAF Patient Assistance Program	Financial Assistance
839	Cancer Fund of America	Financial Assistance
840	National Transplant Assistance Fund	Financial Assistance
871	First Hand Foundation	Financial Assistance
695	Alexander G. Bell Association for the Deaf – Grant for infant and pre-school age	Financial Assistance
446	Montgomery County -Child Care Subsidy Program	Financial Assistance / Child Care
891	The Genentech Endowment for Cystic Fibrosis	Financial Assistance / Pharmacy Program
750	Tobramycin Solution for Inhalation Therapy (TOBI) Foundation	Financial Assistance / Pharmacy Programs
0	Maryland DHR/DSS	Government Resources
1	Anne Arundel County – DSS	Government Resources
2	Allegany County – DSS	Government Resources
3	Cecil County – DSS	Government Resources
4	Baltimore City – DSS	Government Resources
5	Carroll County – DSS	Government Resources
6	Baltimore County – DSS	Government Resources
7	Calvert County – DSS	Government Resources
8	Dorchester County – DSS	Government Resources
9	Frederick County - DSS	Government Resources
[illegible]	Garrett County – DSS	Government Resources
[illegible]	Harford County – DSS	Government Resources
[illegible]	Howard County – DSS	Government Resources
13	Kent County – DSS	Government Resources
14	Montgomery County- DSS	Government Resources
15	Prince George's County – DSS	Government Resources
16	Charles County – DSS	Government Resources
17	Queen Anne's County – DSS	Government Resources
18	St. Mary's County – DSS	Government Resources
19	Somerset County – DSS	Government Resources
20	Talbot County – DSS	Government Resources
21	Washington County – DSS	Government Resources
22	Wicomico County – DSS	Government Resources
23	Worcester County – DSS	Government Resources
24	Caroline County – DSS	Government Resources
221	Adult Protection Services Prince George's County	Government Resources
234	Attorney General's Office of Consumer Protection	Government Resources
236	Chamber of Commerce – Frederick Co.	Government Resources
253	Housing Authority of the City of Frederick	Government Resources
326	Maryland Lead Poisoning Division	Government Resources
359	Maryland Department of Aging	Government Resources
360	Worcester County – Senior Information & Assistance Center	Government Resources
361	MD Area Agency on Aging – Allegany County	Government Resources
[illegible]	MD Area Agency on Aging – Anne Arundel Co.	Government Resources
[illegible]	MD Area Agency on Aging – Baltimore City	Government Resources
[illegible]4	MD Area Agency on Aging – Baltimore County	Government Resources
365	MD Area Agency on Aging – Calvert County	Government Resources
366	MD Area Agency on Aging – Kent/Caroline/Talbot Counties – Upper Shore Aging	Government Resources
367	MD Area Agency on Aging – Carroll County	Government Resources

368	MD Area Agency on Aging – Cecil County	Government Resources
369	MD Area Agency on Aging – Charles County	Government Resources
370	MD Area Agency on Aging – Dorchester/Somerset/Wicomico Counties	Government Resources
[illegible]	Frederick County Dept. of Aging	Government Resources
[illegible]	MD Area Agency on Aging – Garrett County	Government Resources
[illegible]73	MD Area Agency on Aging – Harford County	Government Resources
374	Howard County – Office on Aging	Government Resources
375	MD Area Agency on Aging – Montgomery County	Government Resources
376	MD Area Agency on Aging – Prince George's County	Government Resources
377	MD Area Agency on Aging – Queen Anne's County	Government Resources
378	MD Area Agency on Aging – St. Mary's County – Dept. of Aging	Government Resources
379	MD Area Agency on Aging – Washington County	Government Resources
400	Access Board	Government Resources
401	ADA Information for the Mid-Atlantic Region	Government Resources
403	Maryland Codes Administration	Government Resources
404	Montgomery County Permitting Service Dept.	Government Resources
405	Dept. of Health and Human Services – Accountability and Customer	Government Resources
406	Office of Human Rights	Government Resources
407	MC Public Schools – Diversity and Training	Government Resources
457	Commission on Disabilities – Baltimore County	Government Resources
458	Dept. of Citizen Services – Carroll County	Government Resources
459	Commission on Disabilities – Frederick County	Government Resources
460	Department of Disabilities	Government Resources
[illegible]	Department of Community Resources – Harford County	Government Resources
462	Commission on Disability Services - Howard County	Government Resources
463	Commission on People with Disabilities – Montgomery County	Government Resources
464	Commission on Individuals with Disabilities – Prince George's County	Government Resources
465	Committee on the Disabled – St. Mary's County	Government Resources
808	HRSA Information Center	Government Resources
828	Maryland DDA	Government Resources
634	Planning Now – Resource Guide	Government Resources / Planning
110	Maryland Rehabilitation Center	Government Resources, Vocational/Rehabilitation Services
121	MD Department of Rehab. (DORS) - Central	Government Resources, Vocational/Rehabilitation Services
122	MD Department of Rehab. (DORS) - Workforce Technology Center	Government Resources, Vocational/Rehabilitation Services
123	MD Department of Rehab. (DORS) -Client Assistance	Government Resources, Vocational/Rehabilitation Services
124	MD Department of Rehab. (DORS) - Disability Determination	Government Resources, Vocational/Rehabilitation Services
125	MD Department of Rehab. (DORS) - Hagerstown, Regional	Government Resources, Vocational/Rehabilitation Services
126	MD Department of Rehab. (DORS) - Hagerstown, Local	Government Resources, Vocational/Rehabilitation Services
[illegible]	MD Department of Rehab. (DORS) - Cumberland	Government Resources, Vocational/Rehabilitation Services
[illegible]	MD Department of Rehab. (DORS) - Frederick	Government Resources, Vocational/Rehabilitation Services
129	MD Department of Rehab. (DORS) - Westminster	Government Resources, Vocational/Rehabilitation Services
130	MD Department of Rehab. (DORS) - Oakland	Government Resources, Vocational/Rehabilitation Services
131	MD Department of Rehab. (DORS) - Frederick Business Center	Government Resources, Vocational/Rehabilitation Services

132	MD Department of Rehab. (DORS) - Annapolis – Regional	Government Resources, Vocational/Rehabilitation Services
133	MD Department of Rehab. (DORS) - Annapolis – Local	Government Resources, Vocational/Rehabilitation Services
1[illegible]	MD Department of Rehab. (DORS)- Glen Burnie	Government Resources, Vocational/Rehabilitation Services
[illegible]	MD Department of Rehab. (DORS) - Waldorf	Government Resources, Vocational/Rehabilitation Services
136	MD Department of Rehab. (DORS) - Leonardtown	Government Resources, Vocational/Rehabilitation Services
137	MD Department of Rehab. (DORS) - Prince Frederick	Government Resources, Vocational/Rehabilitation Services
138	MD Department of Rehab. (DORS) - Baltimore City	Government Resources, Vocational/Rehabilitation Services
139	MD Department of Rehab. (DORS) - Salisbury	Government Resources, Vocational/Rehabilitation Services
140	MD Department of Rehab. (DORS) - Cambridge	Government Resources, Vocational/Rehabilitation Services
141	MD Department of Rehab. (DORS) - Easton	Government Resources, Vocational/Rehabilitation Services
142	MD Department of Rehab. (DORS) - Elkton	Government Resources, Vocational/Rehabilitation Services
143	MD Department of Rehab. (DORS) - Towson-Regional	Government Resources, Vocational/Rehabilitation Services
144	MD Department of Rehab. (DORS) - Towson	Government Resources, Vocational/Rehabilitation Services
145	MD Department of Rehab. (DORS) – Bel Air	Government Resources, Vocational/Rehabilitation Services
146	MD Department of Rehab. (DORS) – Catonsville	Government Resources, Vocational/Rehabilitation Services
147	MD Department of Rehab. (DORS) – Dundalk	Government Resources, Vocational/Rehabilitation Services
148	MD Department of Rehab. (DORS) - Ellicott City	Government Resources, Vocational/Rehabilitation Services
149	MD Department of Rehab. (DORS) - Lanham	Government Resources, Vocational/Rehabilitation Services
150	MD Department of Rehab. (DORS) - Wheaton	Government Resources, Vocational/Rehabilitation Services
151	MD Department of Rehab. (DORS) - Oxon Hill	Government Resources, Vocational/Rehabilitation Services
152	MD Department of Rehab. (DORS) - Germantown	Government Resources, Vocational/Rehabilitation Services
1[illegible]	MD Department of Rehab. (DORS) - D.C. Suburbs - Regional	Government Resources, Vocational/Rehabilitation Services
[illegible]	Columbia Lighthouse for the Blind	Hearing / Visually Impaired
[illegible]9	National Association of the Deaf	Hearing / Visually Impaired
482	Services for the Visually Impaired	Hearing / Visually Impaired
497	Better Hearing Institute	Hearing / Visually Impaired
499	Montgomery County Association for the Deaf	Hearing / Visually Impaired
556	The Gateway School – Hearing and Speech Agency	Hearing / Visually Impaired
591	Guiding Eyes for the Blind	Hearing / Visually Impaired
'11	Guide Dog Foundation for the Blind	Hearing / Visually Impaired
'14	New Eyes for the Needy	Hearing / Visually Impaired
'15	Pilot Dogs Inc.	Hearing / Visually Impaired
22	National Federation of the Blind	Hearing/Visually Impaired
53	Community Care Nursing	Home Health Care
55	New Care Home Health Services	Home Health Care
56	Infinity Nursing Services	Home Health Care
58	All About Home Care	Home Health Care
59	Crystal Health Care	Home Health Care
61	Home Helpers	Home Health Care
80	Advanced Nursing and Home Support	Home Health Care
81	BT HealthCare Services	Home Health Care
97	Compassionate Care Health Services	Home Health Care
11	Johns Hopkins Respiratory Program	Home Health Care
00	Generations Nursing Agency	Home Health Care
51	Helping Hands Medical Service	Home Health Care
52	Pioneer Healthcare Services	Home Health Care
[illegible]	Priority Nursing Care Inc.	Home Health Care
[illegible]	Provide a Nurse	Home Health Care
[illegible]2	BMA Healthcare	Home Health Care
13	Eron's Home and Personal Care	Home Health Care
15	Reliable Care Services	Home Health Care
19	T&N Reliable Nursing Services	Home Health Care
24	Unique Nurses Inc.	Home Health Care
[illegible]0	Family and Nursing Care	Home Health Care

592	Home Call Inc.	Home Health Care
605	Access Nursing Services	Home Health Care
606	Automatic Nursing Care Service	Home Health Care
608	Nursing Enterprises	Home Health Care
	Upper Chesapeake Health / St. Joseph Home Care and Choice Care	Home Health Care
[redacted]1	Chesapeake Potomac Home Health Agency	Home Health Care
612	P - B Health Home Care Agency Inc.	Home Health Care
613	Adventist Home Health	Home Health Care
614	Adventist Home Assistance	Home Health Care
615	Adventist Choice Nursing	Home Health Care
617	AMK Nursing Registry	Home Health Care
618	Aathome	Home Health Care
620	Assurance Healthcare Services	Home Health Care
621	Chesapeake Home Health	Home Health Care
622	Community Home Health of Maryland	Home Health Care
623	Comprehensive Nursing	Home Health Care
624	FMH Home Health Services	Home Health Care
625	Home Health Connection	Home Health Care
627	Integrated Care Management	Home Health Care
628	Johns Hopkins Home Health Services	Home Health Care
629	Johns Hopkins Pediatrics at Home	Home Health Care
630	Med Star Health Visiting Nurse Association	Home Health Care
632	Omni Nurse Associates Inc.	Home Health Care
635	Potomac Home Health Care	Home Health Care
636	Potomac Home Support	Home Health Care
637	Personal Touch Home Care of Baltimore	Home Health Care
638	Peninsula Regional Home Care	Home Health Care
639	Southern MD Home Health Services	Home Health Care
640	Staff Builders Home Health Care	Home Health Care
64[redacted]	Tri-State Home Health & Equipment	Home Health Care
[redacted]	Visiting Nurse Association of MD	Home Health Care
[redacted]4	Western MD Health System and Home Care	Home Health Care
645	Home Health Care Services LLC-MD	Home Health Care
647	Stella Maris, Home Care	Home Health Care
652	Bayada Nurses	Home Health Care
653	Bayada Nurses – Baltimore	Home Health Care
658	Holy Cross – House Calls	Home Health Care
659	Holy Cross – Private Home Care	Home Health Care
660	North Arundel Hospital Home Care	Home Health Care
661	MGH Community Health Home Care	Home Health Care
663	Interim Health Care – Baltimore, MD	Home Health Care
666	Medical Staffing Service	Home Health Care
667	NQRC	Home Health Care
668	Nursing and Healthcare Training Services	Home Health Care
670	PRN Inc.	Home Health Care
671	Professional Nursing Services	Home Health Care
672	Thomas Patient Care Services	Home Health Care
674	Tender Loving Care –Staff Builders – Baltimore	Home Health Care
675	Chester River Home Care and Hospice	Home Health Care
676	Shore Home Care – Home Health & Hospice	Home Health Care
677	Home Health Care – Washington County Hospital	Home Health Care
678	Coastal Hospice – Hospice Care	Home Health Care
679	Coastal Hospice – Home Health	Home Health Care
680	Garrett County – Health Dept. Home Health	Home Health Care
68[redacted]	Royal Nurses	Home Health Care
[redacted]	Lutheran Home Care	Home Health Care
[redacted]3	Prof. Healthcare Resources – Annandale	Home Health Care
684	Prof. Healthcare Resources – Bethesda	Home Health Care
685	Prof. Healthcare Resources – Washington D.C.	Home Health Care
686	Prof. Healthcare Resources – Lanham	Home Health Care
687	Americare In-Home Nursing	Home Health Care
688	Bel Care Inc. Health Care at Home Ltd.	Home Health Care

	Home Health Corp. of America / Professional	Home Health Care
689	Home Health Care	Home Health Care
690	Baltimore. Co. Home Health Services	Home Health Care
716	Care Plus Health Inc.	Home Health Care
7	At Home Care Inc.	Home Health Care
[redacted]	Amos Associates	Home Health Care
92	Visiting Angels - Living Assistance Services	Home Health Care
918	Capital Home Care Inc.	Home Health Care / Hospice
641	St. Agnes Hospital Home Care and Hospice	Hospice
76	Hospice of the Chesapeake	
	Hospice of the Chesapeake - Prince George's	Hospice
77	County	Hospice
78	Hospice of the Chesapeake - Hospice House	Hospice
254	Hospice of Frederick County	Hospice
548	Montgomery Hospice	Hospice
582	Edmarc Hospice	Hospice
609	Upper Chesapeake Health / Harford Hospice	Hospice
619	Hospice Caring- A different Kind of Hospice	Hospice
648	Stella Maris, Hospice Care	Hospice
654	Hospice of Washington County	Hospice
657	Holy Cross – Home Hospice Services	Hospice
691	Heartland Home Healthcare – Sincerus Care	Hospice
692	Heartland Hospice	Hospice
	Heartland Hospice Services for Nursing Home	
693	Residents	Hospice
721	Bon Secours Richmond – Hospice Services	Hospice
724	Hospice of Baltimore	Hospice
725	Capital Hospice	Hospice
726	Halquist House	Hospice
727	Seasons Hospice	Hospice
	Seasons Hospice – Northern Chesapeake	
[redacted]	Division	Hospice
9	Community Hospice	Hospice
730	Community Hospice of Virginia	Hospice
731	Community Hospice of Maryland	Hospice
732	Community Hospice of Washington – Inpatient	Hospice
733	Joseph Richey Hospice	Hospice
734	Carroll Hospice	Hospice
735	Jewish Social Service Agency Hospice	Hospice
911	Blue Ridge Hospice	Hospice
912	Hospice of the Rapidan	Hospice
913	Hospice Support Care	Hospice
914	Hospice Support Care of Williamsburg	Hospice
36	Home Call Hospice – Columbia	Hospice / Home Health Care
174	Shriners Hospitals	Hospitals and Health Facilities
175	Shriners Hospitals - Boston	Hospitals and Health Facilities
176	Shriners Hospitals - Canada	Hospitals and Health Facilities
177	Shriners Hospitals - Chicago	Hospitals and Health Facilities
178	Shriners Hospitals - Cincinatti	Hospitals and Health Facilities
179	Shriners Hospitals - Erie	Hospitals and Health Facilities
180	Shriners Hospitals - Galveston	Hospitals and Health Facilities
181	Shriners Hospitals - Greeneville	Hospitals and Health Facilities
182	Shriners Hospitals - Honolulu	Hospitals and Health Facilities
183	Shriners Hospitals - Houston	Hospitals and Health Facilities
184	Shriners Hospitals - Intermountain	Hospitals and Health Facilities
185	Shriners Hospitals - Lexington	Hospitals and Health Facilities
1[redacted]	Shriners Hospitals - Los Angeles	Hospitals and Health Facilities
	Shriners Hospitals - Mexico	Hospitals and Health Facilities
[redacted]8	Shriners Hospitals - Northern California	Hospitals and Health Facilities
189	Shriners Hospitals - Philadelphia	Hospitals and Health Facilities
190	Shriners Hospitals - Portland	Hospitals and Health Facilities
191	Shriners Hospitals - Shreveport	Hospitals and Health Facilities
192	Shriners Hospitals - Spokane	Hospitals and Health Facilities
193	Shriners Hospitals - Springfield	

194	Shriners Hospitals - St. Louis	Hospitals and Health Facilities
195	Shriners Hospitals - Tampa	Hospitals and Health Facilities
196	Shriners Hospitals - Twin Cities	Hospitals and Health Facilities
197	Matilda Koval Health Center	Hospitals and Health Facilities
1	Middlesex Medical Center	Hospitals and Health Facilities
[redacted]3	Cumberland Hospital for Children	Hospitals and Health Facilities
[redacted]299	Children's Hospital	Hospitals and Health Facilities
310	HSC Pediatric Center	Hospitals and Health Facilities
342	GBMC Community Family Health Center	Hospitals and Health Facilities
507	Shepherd's Clinic	Hospitals and Health Facilities
508	Highlandtown Community Health Clinic	Hospitals and Health Facilities
512	Highlandtown Specialty Clinic	Hospitals and Health Facilities
513	Bel Air Edison Family Health	Hospitals and Health Facilities
514	Baltimore Medical- Annapolis Road	Hospitals and Health Facilities
515	Baltimore Medical- Falls Road	Hospitals and Health Facilities
301	National AIDS Hotline	Hotlines
402	ADA Information Line – Dept. of Justice	Hotlines
473	HOTLINE- Montgomery County	Hotlines
509	National Hispanic Family Health Help Line	Hotlines
510	National Hispanic Prenatal Help Line	Hotlines
851	First Call for Help (United Way in Central MD)	Hotlines
495	Birnbaum Interpreting Services	Interpreters & Translation Services
496	Carrie, Quigley and Associates Inc.	Interpreters & Translation Services
807	The Health Resource Inc.	Medical Information
328	MS Active Source	Medical Information Soruces
345	Pediatric / Adolescent Gastroesophageal Reflux Association (PAGER)	Medical Information Soruces
334	Taking the Fear out of Cancer	Medical Information Soruces / Resource Directories
64	MS Awareness Foundation	Medical Information Sources
65	MS Lifelines	Medical Information Sources
6	MS Pathways	Medical Information Sources
[redacted]	All About Multiple Sclerosis	Medical Information Sources
265	National Information Center for Children & Youth with Disabilities (NICHCY)	Medical Information Sources
302	Emergency Medical Services for Children – Resource Center	Medical Information Sources
304	Rare Cancer Alliance	Medical Information Sources
388	Cystic Fibrosis Information	Medical Information Sources
390	Oley Foundation	Medical Information Sources
408	National Rehabilitation Information Center	Medical Information Sources
409	Cancersource Kids	Medical Information Sources
423	National Rehabilitation Information Center – NARIC	Medical Information Sources
567	Association of Cancer Online Resources	Medical Information Sources
572	Bandaides & Blackboards	Medical Information Sources
602	CF Roundtable	Medical Information Sources
646	Cystic Fibrosis Web Ring	Medical Information Sources
651	The National Center of Home Medical Initiatives for Children with Special Needs	Medical Information Sources
747	CFHeart2Heart	Medical Information Sources
748	Cystic Fibrosis Medicine	Medical Information Sources
749	Cystic Fibrosis Worldwide	Medical Information Sources
751	www.yourlunghealth.org	Medical Information Sources
753	www.kidshealth.org	Medical Information Sources
757	Society for Muscular Dystrophy Information, Int'l	Medical Information Sources
76	www.dmdoptions.com	Medical Information Sources
[redacted]	www.twinenterprises.com/cp	Medical Information Sources
[redacted]4	Fight SMA	Medical Information Sources
768	www.improvingchroniccare.org	Medical Information Sources
769	Children's Cause for Cancer Advocacy	Medical Information Sources
777	4girls Health	Medical Information Sources
782	Birth Defect Research for Children	Medical Information Sources
805	Genetic Alliance	Medical Information Sources

814	www.cancer.com	Medical Information Sources
815	www.chemocare.com	Medical Information Sources
816	Mayo Clinic Online	Medical Information Sources
817	People Living with Cancer	Medical Information Sources
818	M.D. Anderson Cancer Center	Medical Information Sources
[redacted]	www.cancerfacts.com	Medical Information Sources
[redacted]	www.oncolink.com	Medical Information Sources
825	Cancer-Pain	Medical Information Sources
827	Pediatric Oncology Resource Center	Medical Information Sources
844	National Rehabilitation Information Center	Medical Information Sources
845	HealthCareCoach.com	Medical Information Sources
846	Health Pages	Medical Information Sources
847	Healthfinder	Medical Information Sources
848	National Library of Medicine	Medical Information Sources
849	Medline Plus	Medical Information Sources
852	Health Information Resource Database	Medical Information Sources
853	Combined Health Information Database	Medical Information Sources
864	Teens Living with Cancer	Medical Information Sources
874	Maternal and Child Health Library	Medical Information Sources
890	Cystic Fibrosis Information from Pulmozyme	Medical Information Sources
	MD DHMH Community Resource Choice	
898	Healthchoice provider directory	Medical Information Sources
903	Mdchoice.com	Medical Information Sources
397	Beach Center on Disability	Medical Information Sources / Resource Directories
429	Growthhouse	Medical Information Sources / Resource Directories
466	Hope Street Kids	Medical Information Sources / Resource Directories
737	Cure Search	Medical Information Sources / Resource Directories
740	www.healingwell.com	Medical Information Sources / Resource Directories
901	Health Information Center – Wheaton Library	Medical Information Sources / Resource Directories
854	Respite Match.com	Medical Information Sources / Respite Care
741	www.CysticFibrosis.com	Medical Information Sources / Support Groups
[redacted]	65 Roses	Medical Information Sources / Support Groups
[redacted]	Cystic-L	Medical Information Sources / Support Groups
755	www.BeckerMuscularDystrophy.org	Medical Information Sources / Support Groups
	FacioscapuloHumeral Muscular Dystrophy	
756	Society	Medical Information Sources / Support Groups
759	Hope for Muscular Dystrophy	Medical Information Sources / Support Groups
780	Our-Kids	Medical Information Sources / Support Groups
820	www.cancersource.com	Medical Information Sources / Support Groups
872	BMT Infonet	Medical Information Sources / Support Groups
346	KidsCope	Medical Information Sources/ Self-Esteem
791	ICan.com	Medical Information Sources/ Support Groups
873	National Cancer Institute	Medical Information Sourrces / Support Groups
161	Dr. T. Garrillo	Medical Providers
172	Developmental Evaluation Clinic	Medical Providers
173	Center for Spina Bifida	Medical Providers
244	Endocrine and Diabetes Associates	Medical Providers
248	Hagerstown Reproductive Health	Medical Providers
340	Union Memorial Spectrum Dental	Medical Providers
	UMB Dental School – Adult emergency Care	
341	Clinic	Medical Providers
343	Children's Hospital Dentistry	Medical Providers
344	Mitcherling & Mitcherling DDS	Medical Providers
348	Robert B. Testani DDS	Medical Providers
349	North Point Dental	Medical Providers
350	Maurice W. Blakely, DDS	Medical Providers
	Allan M. Dworkin, DDS- Cross Keys Dental	
[redacted]	Associates	Medical Providers
[redacted]	Kernan Hospital	Medical Providers
353	Billy Davis, DDS	Medical Providers
551	Dental Practice of Dr. Katz and Dr. Jimenez	Medical Providers
552	Richard L. Rubin, DDS / Vivencio Reyes DDS	Medical Providers
553	Karl Pick, DDS	Medical Providers
554	Carol Orlando, DDS	Medical Providers

555	UMD Oral Maxillofacial Surgery Associates	Medical Providers
586	A Mission of Mercy	Medical Providers
494	Auditory Services, Inc.	Medical Providers / Hearing/Visually Impaired
2	Brooklane Mental Health Center Programs - Elder Care	Mental Health
[redacted]	Brooklane Mental Health Center Programs - Child and Adolescent	Mental Health
31	Brooklane Mental Health Center Programs - Special Education	Mental Health
32	Brooklane Mental Health Center Programs - Substance Abuse	Mental Health
33	Brooklane Mental Health Center Programs - Pastoral Counseling	Mental Health
34	Brooklane Mental Health Center Programs - Abundant Life Counseling	Mental Health
35	Brooklane Mental Health Center Programs - Transitional Program	Mental Health
168	The Care Clinic	Mental Health
225	Mental Health Association – Frederick	Mental Health
240	Counseling Services	Mental Health
256	American Association of Pastoral Counselors	Mental Health
263	National Association for the Terminally ill	Mental Health
322	family-marriage-counseling.com	Mental Health
355	American Association for Marriage & Family Therapy	Mental Health
470	Center for Families in Transition	Mental Health
475	Jewish Social Services Counseling	Mental Health
489	Rock Creek Foundation for Mental Health – Affiliated Sante Group	Mental Health
490	St. Luke's House	Mental Health
5[redacted]	Way Station	Mental Health
[redacted]	Way Station – Howard County	Mental Health
[redacted]7	NAMI (National Association of Mental Illness)	Mental Health
904	ProBono Counseling Project	Mental Health
433	Shady Grove Adventist Nursing	Nursing Home
593	St. Catherine's Nursing Home	Nursing Home
323	Cystic Fibrosis Services Pharmacy	Pharmacy Programs
694	Special Needs Alliance	Planning
40	Camp Kaleidescope – Alexandria, VA	Recreation and Camps
41	Camp Teen Scene -Therapeutic Recreation Activities – Alexandria, VA	Recreation and Camps
42	After School Program - Therapeutic Recreation Activities – Alexandria, VA	Recreation and Camps
43	Little Dippers - Therapeutic Recreation Activities – Alexandria, VA	Recreation and Camps
44	Kingfishers -Therapeutic Recreation Activities – Alexandria, VA	Recreation and Camps
45	Young Adults Club -Therapeutic Recreation Activities – Alexandria, VA	Recreation and Camps
46	Adult Social Club -Therapeutic Recreation Activities – Alexandria, VA	Recreation and Camps
47	Recreation Buddy -Therapeutic Recreation Activities – Alexandria, VA	Recreation and Camps
48	Recreation Companion -Therapeutic Recreation Activities – Alexandria, VA	Recreation and Camps
4[redacted]	Afterschool Mainstreaming -Therapeutic Recreation Activities – Alexandria, VA	Recreation and Camps
[redacted]	TOP Soccer -Therapeutic Recreation Activities – Alexandria, VA	Recreation and Camps
51	Art Works -Therapeutic Recreation Activities – Alexandria, VA	Recreation and Camps
52	Saturday Social Club -Therapeutic Recreation Activities – Alexandria, VA	Recreation and Camps

86-94	Children's Hospital – Recreation & Educational Programs	Recreation and Camps
218	The Silver Lining Foundation for Kids with Cancer	Recreation and Camps
2[illegible]	Therapeutic and Recreational Riding Center Inc.	Recreation and Camps
[illegible]	Children's Museum of Rose Hill Manor	Recreation and Camps
[illegible]4	The Hole in the Wall Gang Camp	Recreation and Camps
419	Boggy Creek Gang	Recreation and Camps
502	The League for People with Disabilities – Camp Greentop	Recreation and Camps
506	Camp Glow	Recreation and Camps
516	Access Adventures	Recreation and Camps
517	Accessible Journeys	Recreation and Camps
518	Camp Superkids by the American Lung Association	Recreation and Camps
519	Camp Honeybee	Recreation and Camps
520	Club Venture by the ARC of Baltimore	Recreation and Camps
521	Camp Pecometh	Recreation and Camps
522	Camp Attaway	Recreation and Camps
523	Camp Winfield	Recreation and Camps
524	Camp Glencoe	Recreation and Camps
526	Trips Inc. – Special Adventures	Recreation and Camps
527	Rebounders Gymnastics (I Can Do It Too) for Children with Special Needs	Recreation and Camps
528	Camp Chatterbox	Recreation and Camps
529	Camp Huntington	Recreation and Camps
530	Camp Lee Mar	Recreation and Camps
531	Camp Virginia Jaycee	Recreation and Camps
532	Camp Sky Ranch	Recreation and Camps
5[illegible]	CRAB – Chesapeake Region Accessible Boating	Recreation and Camps
[illegible]	The Guided Tour Inc.	Recreation and Camps
[illegible]	4 Steps Therapeutic Riding – Hoofprints in the Sand	Recreation and Camps
536	Kamp A Komplish	Recreation and Camps
537	Keystone Pocono Camp	Recreation and Camps
538	YAI – Mainstreaming at Camp	Recreation and Camps
539	Maryland Therapeutic Riding Inc.	Recreation and Camps
540	Linc Summer Arts Camp	Recreation and Camps
541	Camp Fairlee Manor – Easter Seals	Recreation and Camps
542	Pennsylvania Lions Beacon Lodge Camp	Recreation and Camps
543	Roundlake Camp	Recreation and Camps
544	Camp Glyndon for Children with Diabetes and Deaf Children	Recreation and Camps
549	The Fells Point Summer Drama Camp for Special Needs Children	Recreation and Camps
557	Search Beyond Adventures	Recreation and Camps
558	Easter Seals – Cruises for Kids	Recreation and Camps
559	Four H Therapeutic Riding Program of Carroll County	Recreation and Camps
560	Towson University Dance for Special Children	Recreation and Camps
561	Summer Adventure Camp by Lynne Israel	Recreation and Camps
562	The Sky is the Limit Creative Arts Program	Recreation and Camps
563	Freedom Hills Therapeutic Riding Program	Recreation and Camps
568	Children's Oncology Camping Association	Recreation and Camps
5[illegible]	4 H – Therapeutic Riding Center – Frederick County	Recreation and Camps
[illegible]	Life Horse – Therapeutic Riding Program	Recreation and Camps
[illegible]6	Camp Merry Heart	Recreation and Camps
598	Camp Easter Seals East	Recreation and Camps
599	Camp Holiday Trails	Recreation and Camps
738	Special Love for Children with Cancer	Recreation and Camps
867	Camp Quality USA	Recreation and Camps
868	Camp Ronald McDonald for Good Times	Recreation and Camps

181	Potomac Community Resources	Recreation and Camps / Support Groups
504	The League for People with Disabilities – Wellness Center	Recreation and Camps / Therapeutic Services
370	Island Dolphin Care	Recreation and Camps / Therapeutic Services
57[illegible]	The Resource Network at Kennedy Krieger	Resource Directories
[illegible]2	HSC Foundation – Resource Directory	Resource Directories
[illegible]5	Brave Kids	Resource Directories
772	Through the Looking Glass	Resource Directories
776	ARCH National Respite Network	Resource Directories
778	Disability Central	Resource Directories
779	Kids Together	Resource Directories
783	Children with Spina Bifida: A Resource Page for Parents	Resource Directories
784	Developmental Delay Resources	Resource Directories
785	Family Friendly Fun	Resource Directories
787	Parents Helping Parents	Resource Directories
788	Developmental Disability.org	Resource Directories
789	Down Syndrome Empowerment Network	Resource Directories
792	Information Center for Individuals with Disabilities	Resource Directories
793	Cornucopia of Disability Information	Resource Directories
795	Disability Online	Resource Directories
796	Disability Resources Inc.	Resource Directories
797	Family Village	Resource Directories
798	International Center for Disability Resources on the Internet	Resource Directories
799	New Horizons Unlimited	Resource Directories
842	Disabilityguide.org	Resource Directories
881	Our Final Journey	Resource Directories
89	NAHC – Home Care and Hospice Agency Locator	Resource Directories
[illegible]0	Disabilityinfo.gov	Resource Directories
[illegible]6	Grants for Individuals: The Disabled	Resource Directories
915	Resource Guides fo People with Developmental Disabilities / Links	Resource Directories
916	Disability Network Directory - Montgomery County	Resource Directories
917	Guide to Retirement Living	Resource Directories
338	Community Connections	Resource Directories / Community Resources
786	IRSC Internet Resources for Special Children	Resource Directories / Support Groups
73	Bello Machre - Respite Care	Respite Care
255	Maple Shade Clinic – Respite Care Services	Respite Care
308	ARC of Prince George's County Respite Care Home	Respite Care
545	Caring Hands Inc.	Respite Care
577	Kennedy Krieger – Respite Care	Respite Care
579	Way Station – Child & Adolescent Programs – Respite Care – Camp Journey	Respite Care
626	Respite Services of Montgomery County	Respite Care
330	Make a Child Smile	Self-Esteem
332	Locks of Love	Self-Esteem
357	Caringbridge	Self-Esteem
358	Captain Chemo	Self-Esteem
565	Hugs and Hope for Sick Children	Self-Esteem
304	Heavenly Hats Foundation	Self-Esteem
533	Chemo Angels	Self-Esteem
[illegible]3	Look Good...Feel Better (for people in cancer treatment)	Self-Esteem
[illegible]9	Talking Wellness	Self-Esteem
182	Songs of Love	Self-Esteem
185	Visitingours.com	Self-Esteem
187	Angels of Destiny	Self-Esteem
193	Keiki Cards	Self-Esteem
[illegible]	SHARP'S Natural Haire Care & Wellness	Self-Esteem

205	Jefferson School (part of Sheppard Pratt)	Special Education / Information and Laws
209	Parent Educational Advocacy Training Center (PEATC)	Special Education / Information and Laws
38	United Cerebral Palsy of Central Maryland – Delrey School	Special Education / Information and Laws
[redacted]64	United Cerebral Palsy of Central Maryland - Arbutus Development Center	Special Education / Information and Laws
385	United Cerebral Palsy of Central Maryland – Harford Development Center	Special Education / Information and Laws
438	Grafton School	Special Education / Information and Laws
443	Montgomery Primary Achievement Center (MPAC)	Special Education / Information and Laws
449	Dyslexia Tutoring Program	Special Education / Information and Laws
909	Bridges Public Charter School	Special Education / Information and Laws
215	PACER	Special Education / Information and Laws
203	Al Anon / Alateen of Anne Arundel County	Support Groups
207	MUMS national Parent to Parent organization	Support Groups
230	Alcoholics Anonymous – Frederick County	Support Groups
321	MD Society for Cleft Lip and Palate	Support Groups
389	CForward.net	Support Groups
393	Self-Help Sourcebook Online	Support Groups
398	International Cystic Fibrosis Support Groups	Support Groups
399	Rest Ministries	Support Groups
417	Squirrel Tales	Support Groups
467	Al Anon – Alateen Washington Metro Area	Support Groups
478	Narcotics Anonymous	Support Groups
480	Friends Health Connection	Support Groups
754	www.livingfortoday.org	Support Groups
758	Muscular Dystrophy Forum	Support Groups
773	Parents of Children with Downs Syndrome	Support Groups
78	Ability On Line	Support Groups
[redacted]	Disabilties-R-US.com	Support Groups
[redacted]6	Onco-Chat	Support Groups
888	Moms United	Support Groups
803	MS World	Support Groups / Medical Information Sources
869	Group Loop	Support Groups / Medical Information Sources
883	MS Watch	Support Groups / Medical Information Sources
306	Ideal Lives	Support Groups / Resource Directories
331	PatchWorx Inc.	Support Groups / Self-Esteem
373	Cerebral Palsy Ability Center	Therapeutic Services
100	Wheelchair Getaways	Transportation
102	Accessible Vans / Ironside Mobility	Transportation
118	Corporate Angel Network	Transportation
136	Angel Flight	Transportation
603	Patienttravel.org	Transportation
101	Viewpoint Mobility	Transportation / Adaptive Technology
03	Ride Away	Transportation / Adaptive Technology
05	Associated Rollx Vans	Transportation / Adaptive Technology
12	Auto Assist and Wheelchair Getaways	Transportation / Adaptive Technology
27	Wheelchair Mobile Transport	Transportation / Adaptive Technology
37	Scott Key Center	Vocational / Rehabilitation Services
90	Jeanne Bussard Center	Vocational / Rehabilitation Services
84	Byte Back	Vocational/ Rehabilitation Services
98	Jewish Vocational Services	Vocational/ Rehabilitation Services
03	The League for People with Disabilities – League Industries	Vocational/ Rehabilitation Services
[redacted]	The League for People with Disabilities – Vocational Rehabilitation	Vocational/ Rehabilitation Services
57	Frederick County JTA - Business & Employment Center	Vocational/Rehabilitation Services
54	Give Kids the World	Wish Granting Program
8	Kids Wish Network	Wish Granting Programs
60	Dream Foundation	Wish Granting Programs
17	The Sunshine Foundation	Wish Granting Programs

493	Famous Fone Friends	Wish Granting Programs
564	Fairy Godmother Foundation	Wish Granting Programs
580	Make a Wish Foundation of the Mid Atlantic	Wish Granting Programs
581	Make a Wish Foundation – Baltimore	Wish Granting Programs
5[illegible]	Make a Wish Foundation – Western MD	Wish Granting Programs
[illegible]	Marty Lyons Foundation	Wish Granting Programs
[illegible]8	Children's Wish Foundation International	Wish Granting Programs
841	Wishland	Wish Granting Programs
896	Children's Hopes and Dreams Wish Fulfillment Foundation	Wish Granting Programs
897	Wishing Well Foundation USA	Wish Granting Programs
886	Caring Institute	Wish Granting Programs
600		

ATTACHMENT E

Resource Name	ID	Website Address	Brief Description
The Community Resource Directory	662	http://www.hscfoundation.org/	The community services directory provides information on resources to help families/children with special health needs in the National Capital Region. Also available in Spanish.
Children's Hospice International	26	www.chionline.org	A database of institutions caring for children with life-threatening illnesses is available on this web-site.
Planning Now	634	www.md-council.org	This is a publication that discusses future financial planning to assist family members with a disability.
Healing Well	740	www.healingwell.com	This site contains health-oriented information for those dealing with a disease/ chronic illness
Cystic Fibrosis	741	www.cysticfibrosis.com	This web-site provides information relating to Cystic Fibrosis.
65 Roses	742	www.sixtyfiveroses.com	This web-site provides information relating to Cystic Fibrosis.
Cure Search	737	www.curesearch.org	Information is primarily geared towards childhood cancer resources. It also contains information on national associations & care organizations.
Hope Street Kids	466	www.hopestreetkids.org	Information is primarily geared to pediatric cancer patients.
Cystic Fibrosis Medicine	748	www.cysticfibrosismedicine.com	This web-site provides information relating to Cystic Fibrosis.
Your Lung Health	751	www.yourlunghealth.com	Information is primarily geared towards respiratory patients.
Cystic Fibrosis Research	752	www.cfri.org	This web-site provides information relating to Cystic Fibrosis.
FSH Society	756	www.fshsociety.org	Information is primarily geared towards FSH Muscular Dystrophy

NORD	765	www.rarediseases.org	Information is available regarding rare diseases.
Madison's Foundation	766	www.madisonsfoundation.org	Information is available regarding rare life-threatening diseases
Brave Kids	665	www.bravekids.org	The resource directory contains a wide range of information, on a national level.
Chemo Angels	633	www.chemoangels.com	This web-site contains a link to cancer information
Exceptional Parent	223	www.eparent.org	The web-site contains a resource directory for parents of children with disabilities. On-line registration is required to view the web-based version.
Grieftnet	578	www.griefnet.org	This web-site contains information for bereavement.
Growthhouse	429	www.growthhouse.org	This is a web-site that provides access to information regarding end-of-life care and life-threatening illness
CancerSource Kids	409	www.cancersourcekids.com	This is a secure web-site where kids can learn about cancer
Cerebral Palsy Resource Center	761	www.twinenterprises.com/cp	This web-site contains information on Cerebral Palsy
International Cystic Fibrosis Support Group	398	Http://cf.concoll.edu	This web-site provides information relating to Cystic Fibrosis.
Improving Chronic Illness Care	768	www.improvingchroniccare.org	This web-site contains information pertaining to chronic illness.
Association of Cancer Online Resources	567	www.acor.org	This web-site contains information on Cancer
Through the Looking Glass	772	http://lookingglass.org	This web-site contains a resource directory, geared towards those with disabilities or complex-medical needs
Kids Together	779	www.kidstogether.org	This web-site contains information for persons with disabilities.
Our-Kids	780	www.our-kids.org	This is a web-site with information for those caring for or working with children with physical &/ or mental disabilities and delays.
Children with Spina Bifida	783	www.waisman.wisc.edu/~rowley/sb-	This web-site contains information on Spina-Bifida

		kids/index.html	
Developmental Delay Resources	784	www.devdelay.org	This web-site contains information designed to support persons with special needs.
Family Friendly Fun	785	www.family-friendly-fun.com	This web-site offers information of a wide variety of topics for families with disabilities.
Internet Resources for Special Children	786	www.irsc.org	IRSC is a web-site that contains information for children with disabilities and other health disorders.
Parents Helping Parents	787	www.php.com	The web-site contains an online resources section that provides information for children with special needs.
Down Syndrome Empowerment Network	789	www.downsyndrome.com	This web-site contains on-line information regarding Downs Syndrome.
The National Fragile X Foundation	790	www.fragilex.org	This web-site provide information regarding Fragile-X syndrome *available in Spanish
Cornucopia of Disability Information	793	http://codi.buffalo.edu	This web-site contains an internet directory of disability information.
Disability Online	795	www.disabilityonline.com	This web-site contains over 2,000 links to different types of disability information.
Disability Resources Inc.	796	www.disabilityresources.org	This web-site contains a database, and an on-line resource directory to disability information.
Family Village	797	www.familyvillage.wisc.edu	This web-site contains information for those with disabilities and their families
International Center for Disability Resources on the Internet	798	www.icdri.org	This organization has designed a web-site to disseminate information for people with disabilities. *this web page can be translated
New Horizons Un-limited Inc.	799	www.new-horizons.org	This non-profit organization serves people affected by lifelong disability. One of the services is an on-line resource directory.
American Spinal Injury Association	800	www.asia-spinalinjury.org	There are links on the web-site that lead to information about spinal cord injuries.

WAPD	801	www.wapd.org	This web-site contains a resource page, with information for those with disabilities.
Genetic Alliance	805	www.geneticalliance.org	This web-site contains information on a variety of genetic conditions
Ideal Lives	806	www.ideallives.com	This organization provides information regarding support for those raising children with special needs. *registration is required
Cancer.com	814	www.cancer.com	This web-site contains information on Cancer
People Living with Cancer	817	www.plwc.com	This web-site contains information on Cancer
Cancersource	820	www.cancersource.com	This web-site contains information on Cancer
American Association on Mental Retardation	824	www.aamr.org	This web-site provides access to a variety of information regarding those with intellectual disabilities
Pediatric Oncology Resource Center	827	www.acor.org/ped-onc	This web-site contains information on childhood cancer resources, web links and other references.
Maryland DDA	828	http://dhmh.state.md.us/dda_md	This agency oversees the service delivery system for individuals with developmental disabilities. The web-site contains a resource directory with detailed descriptions of various resources and services, as well as information about eligibility, application and other frequently asked questions.
Cancer Fund of America	839	www.cfoa.org	This web-site contains information on Cancer
National Rehabilitation Information Center	844	www.naric.com	This web-site contains an abundance of disability and rehabilitation-oriented information. Examples of information include: on-line publications, searchable databases and reference and referral data.
Healthfinder	847	www.healthfinder.gov	This is an on-line resource for information regarding government and non-profit health and human services information. Information is available in Spanish.
Medline Plus	849	http://medlineplus.gov	This is a web-site for consumer health information,

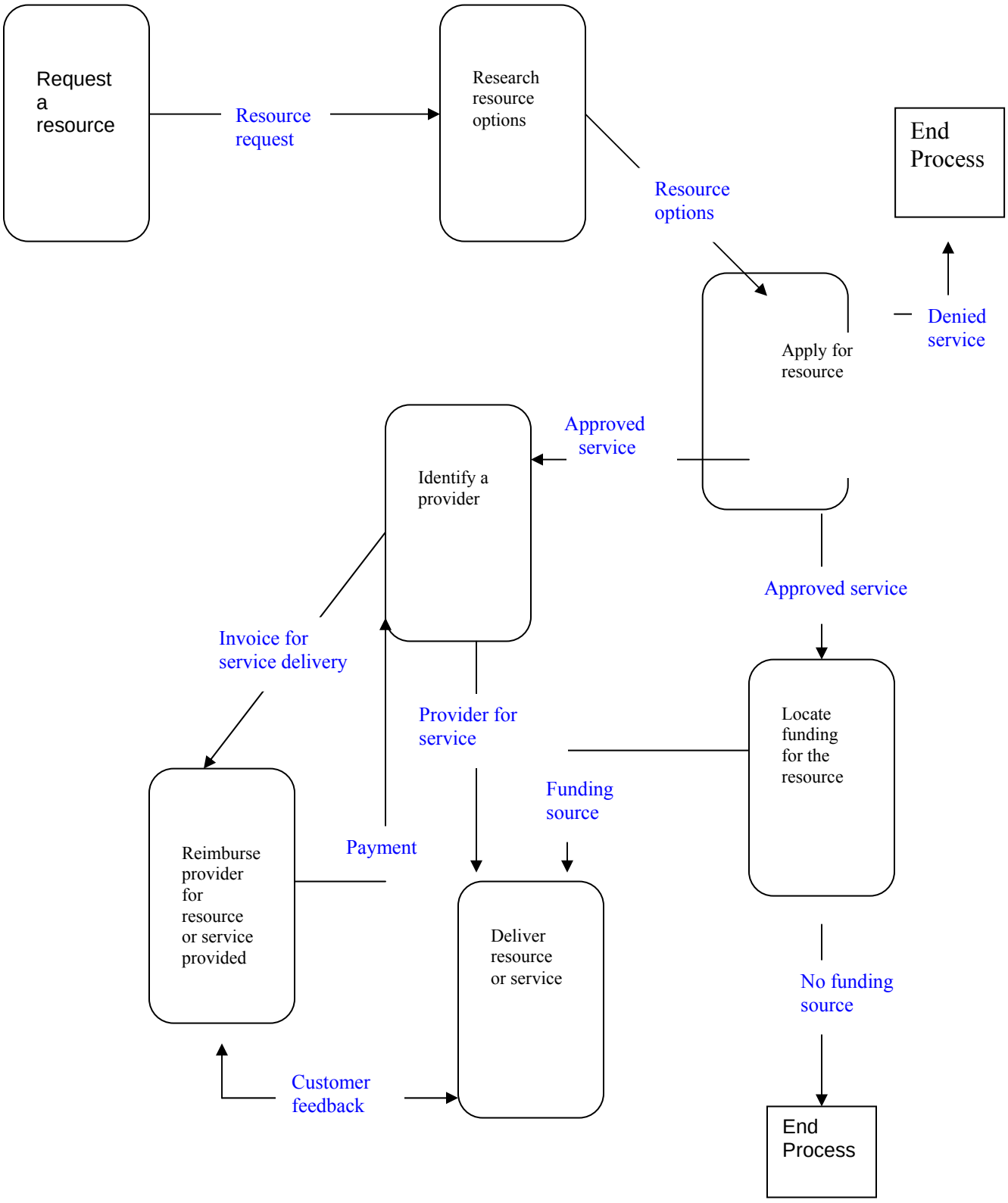
			also available in Spanish. The range of information includes: health topics, medical encyclopedia, health tutorials, drug information, health news, dictionary, directories and other resources (organizations, libraries, databases).
National Health Information Center/Resource Database	852	www.health.gov/nhic/	This is a national health information referral service. Information specialists can refer callers to the appropriate resource. Examples of entries in the database include: disease prevention, federal clearinghouse, foreign language resources, healthcare, health education, public health and school health, among others.
Hospice Foundation of America	616	www.hospicefoundation.org	This web-site contains a variety of information regarding end-of-life issues
National Cancer Institute	873	www.nci.nih.gov	The web-site contains information regarding cancer.
Maternal and Child Health Library	874	www.mchlibrary.info	This web-site contains information regarding Maternal and Child Health
National Dissemination Center for Children with Disabilities	265	www.nichcy.org	The organization provides information on topics regarding children and youth with disabilities, birth through 22.
Beach Center on Disability	397	www.beachcenter.org	The web-site contains resources in English, Spanish, Korean and Chinese, for those with disabilities.
Americans for Better Care of the Dying	394	www.abcd-caring.org	The web-site contains a number of links to useful resources such as: advance care planning, aging, care-giving, chronic illness, end of life hospice, grief, healthcare, pain, relevant organizations
Self-Help Group Sourcebook Online	393	http://mentalhelp.net/selfhelp/	This web-site contains a database of self-help support groups
National Center of Medical Home Initiatives	651	www.medicalcominfo.org	This organization provides support those who care for children with special needs. One can find information

			about what a medical home is and relevant resources on related topics. Information is also available in Spanish.
Cystic Fibrosis Information	388	http://www3.nbnet.nb.ca/normap/CF.htm	This is a web page by a woman with CF. One can also find it by going to Google and typing "Cystic Fibrosis Information" This site contains over 2,000 links to other resources/sites.
Cystic Fibrosis Web Ring	646	http://i.webring.com/hub?ring=cf_ring	This web-site provides information relating to Cystic Fibrosis.
The Wellness Community	821	www.thewellnesscommunity.org	This site contains information for people affected by cancer
Our Final Journey	881	http://endoflifecare.tripod.com/Caregiving/index.html	This web-site contains a variety of useful information for families with a loved one who has a terminal/chronic illness
NAHC Home Care and Hospice Agency Locator	895	www.nahc.org	Through this web-site, individuals/ consumers/ families can access a database of home care/hospice agencies in areas throughout the country. Click on the 'agency' tab on the right hand side of the screen for more information.
Multiple Sclerosis Foundation	899	www.msfocus.org	This non-profit organization focuses on support and educational programs for persons coping with Multiple Sclerosis (MS). One can also obtain publications on MS at no cost. The web-site and multimedia library can be viewed in Spanish.
Disbilityinfo.gov	900	www.disability.gov	This is an on-line resource that contains disability-related information and information on programs available. Topics include: education, employment, housing, health, income support, technology and transportation.
Grants for Individuals: The Disabled	906	http://www.lib.msu.edu/harris23/grants/3disable.htm	This web-site contains information on grants, scholarships and financial aid opportunities for

			individuals with disabilities.
Community Connections	338	www.communityconnections.umd.edu	The resource page lists available resources for children with disabilities / special needs in the local Maryland Metropolitan area
Resource Guides for People with Developmental Disabilities / Links	915	http://www.arcfc.org/resources.html http://www.arcfc.org/links.htm	These are resources compiled by the ARC of Frederick County, catering to people with developmental disabilities. One can download resource directories specific to various counties in the state of Maryland.
Disability Network Directory – Montgomery County	916	http://www.montgomerycountymd.gov/hhstmpl.asp?url=/content/hhs/ads/DisabilityNetworkDirectory/index.asp	This is a directory of providers, agencies, businesses and advocacy organizations for people with disabilities

ATTACHMENT F

Data Flow Diagram
Process for Accessing Resources for Families



ATTACHMENT G

Service Profile Chart

I/R = Info. and Referral

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U
1		Federal Programs			State Programs								Military						Private Insurance	Other Resource	
2	Projected Service and Resource Needs for mCare population	SSI	EPSDT	WIC	Medicaid Categorically Needy	Medicaid Medically Needy	Medicaid Special Populations	DDA Services	I & T Program	Public Education Programs	Social Services	Other (Title V)	Tricare Basic	Tricare ECHO (Active Duty and must meet medical criteria)	EFMP	Military One Source (Active Duty)	Direct Care System (available during hospitalization only)	Other Military Program		Disease based Foundation	Local Resource
3	Physician care (includes primary care and specialty care)				X	X	X					X	X				X		X	I/R	
4	Pharmacy				X	X	X					X	X			I/R	X		X	X	X
5	Durable Medical Equipment (DME)				X	X	X	X	X	X (for educational goals)		X	X	X		I/R			X	X	X
6	Disposable Medical Supplies (DMS)				X	X	X			X (for educational goals)		X	X	X		I/R			X		
7	Nursing (Private Duty Shift Nursing)				X	X	X	X		X (for educational goals)				X		I/R			X		
8	Nursing (Skilled Visits)			X	X	X	X	X		X (for educational goals)		X	X	X		I/R			X		X
9	Home Health Aide				X	X	X	X		X (for educational goals)		X				I/R			X		X
10	Personal Care Services				X	X	X	X		X (for educational goals)						I/R					
11	Social Work Services			X	X	X	X	X	X	X (for educational goals)	X	X	X	X		I/R	X				
12	Nutritional			X	X	X	X	X			X	X	X			I/R	X		X		
13	Pain and Symptom Management				X	X	X					X	X	X		I/R	X		X		
14	Hospice				X	X	X						X			I/R	X		X		
15	Occupational Therapy				X	X	X		X	X (for educational goals)		X	X			I/R	X		X		X
16	Physical Therapy						X		X	X (for educational goals)		X	X			I/R	X		X		X
17	Speech Therapy						X		X	X (for educational goals)		X	X			I/R	X		X		X
18	Respiratory Therapy				X (sometimes bundled with DME)	X (sometimes bundled with DME)	X (sometimes bundled with DME)						X			I/R	X		X (this service is sometimes included with related DME)		
19	Expressive Therapy (ie, music, art, play)						X	X	X	X (for educational goals)						I/R					X
20	Adaptive Equipment (special seating devices, bathchairs, gait trainers, prone standers, car seats for children >40lbs., lifts, etc)				X	X	X	X	X	Some programs will provide loaners			X			I/R	X			X	X
21	Care Coordination						X	X	X	X (for educational goals)	Case Worker	X		X	X (varies dependent on military branch)	I/R	X	X	X	I/R	I/R
22	Respite						X	X				X		X		I/R				X	X
23	Family/ Caregiver Counseling				X	X	X	X	X	X (for educational goals)	X		X			I/R		X	X	X	X
24	Individual Counseling				X	X	X	X			X		X			I/R	X	X	X		
25	Group Counseling				X	X	X	X	X		X					I/R	X			X	X
26	Bereavement Counseling						X									I/R	X		X	X	X
27	Education services							X	X	X (for educational goals)					X	I/R	X (if previously provided by the military)			X	X
28	Dental				X	X	X	X				X	X			I/R	X (if related to a medical condition)	X	X		X

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U
1		Federal Programs			State Programs								Military						Private Insurance	Other Resource	
2	Projected Service and Resource Needs for mCare population	SSI	EPSDT	WIC	Medicaid Categorically Needy	Medicaid Medically Needy	Medicaid Special Populations	DDA Services	I & T Program	Public Education Programs	Social Services	Other (Title V)	Tricare Basic	Tricare ECHO (Active Duty and must meet medical criteria)	EFMP	Military One Source (Active Duty)	Direct Care System (available during hospitalization only)	Other Military Program		Disease based Foundation	Local Resource
29	Child Care (typical and special needs)							X	I/R	X (for educational goals)						I/R		X			X
30	Assistive Technology				X	X	X	X	X	X (for educational goals)		X		X		I/R			X	X	X
31	Behavior Management				X	X	X		X	X (for educational goals)			X (under special circumstances)			I/R	X	X			X
32	Family/ Caregiver Training						X	X								I/R	X			X	X
33	Financial Support	X		X				X			X					I/R		X		X	X
34	Habilitation services (day, residential, prevocational, supported employment							X		X			X (mental health only)			I/R		X		X	X
35	Housing Access Coordination						X	X			X				X	I/R		X		X	X
36	Interpretor/ Translation			X				X	X		X					I/R	X		X	X	X
37	Mental Health				X	X	X	X	I/R		X	X	X			I/R	X			X	X
38	Moving Assistance										X				X	I/R		X			X
39	Transportation - ambulance				X	X	X				X	X	X (for medical monitoring)			I/R	X (for medical monitoring)	X	X		X
40	Transportation - routine medical				X	X	X				X					I/R				X	X
41	Vehicle Modifications				X	X	X	X				X	X (under special circum-stances)			I/R			X	X	X
42	Recreation and camps							X		X	X	X				I/R				X	X
43	Medical Information Source												X			I/R	X		X	X	
44	Wish Granting							X								I/R				X	X
45	Caregiver Resources						X	X	X	X		X				I/R				X	X
46	Self -Esteem support							X	X	X						I/R			X	X	X
47	Advocacy for Child/ Family Needs		X					X	X	X	X	X				I/R				X	X
48	Resource Coordination						X	X	X	X	X		X	X		X	X		X	X	X
49	Family/ Child Education re: healthcare needs)							X	X	X	X	X	X	X			X				
50	Provider Education		X	X	X	X	X	X	X	X		X					X		X	X	X
51	Volunteer Support							X	I/R		X						X	X		X	X
52	Spiritual Care							X								I/R	X	X			X
53	Child Life Services												X (inpatient only)				X (if available at inpatient facility)				

ATTACHMENT H

	Federal	Federal / State	Military	Condition specific	Local Community
***Types* of supports available**	*Income* (SSI) *Standards* for Medicaid's comprehensive and preventative child health program for children < 21 yrs.	DDA *advocacy* for system change, and *service or support programs* *Special Education* services age 6 - 17 with some states expanding services from age 3- 21. *Early Intervention* services for 0 - 3. Medicaid Programs -state plan services *Medicaid Waiver Programs* - for categorically needy, medically needy and special groups *Title V programs* *Social Service programs* - foster care/ adoption, child protective services, etc. *Employment support* services *Legal Protection and Advocacy*	The following categories of resources are referenced on Military HOMEFRONT website and represents types of supports and information available for families across military branches: • Quality of Life Resources • DoD Impact Aid • Education • Child Abuse Prevention • Medical and Dental • Special needs/ EFMP • Education/ Early Intervention • Special Education (3-21 yrs) • Education (> 21) • Medical care/ Tricare • Federal programs/ Title V and Medicaid • Family Connections • Family Support • Financial and Legal • Child Development Programs • Morale, Welfare and Recreation • Parenting • Head Start/ Sure Start • Special discount offers • Commissaries and Exchanges • Deployment • Eldercare • Emergency and Disasters • Employment • Housing and Relocation assistance • Domestic Abuse • Military Severely Injured • Interpersonal Abuse includes domestic • Networking Partnerships	*Variety of Resources* I*nformatio*n (about disease, clinical trials, treatment regimes, etc) *Conferences and presentations* related to the condition	Resources that are specific and targeted as opposed to a program of services. Examples of these include but are not limited to: • Professional providers • Heath information • Adaptive technology • Child care services • Translation services • Recreation and camps • Support groups • Transportation • Respite care • Utility assistance programs • Environmental modifications • Caregiver resources • Case management services • Funding sources • Planning information

			• Relocation Planning • Federal Programs (Medicare)		
Where to find information	• Internet (SSA website, • Military Homefront website) • Local Library • Local SSA office	• Internet (some links on Military Homefront website) • Local Library • Local Departments of Social Services • Local Departments of Education • State offices for Maternal Child Health • Can access information via telephone	• Military OneSource • Military HOMEFRONT website	• Internet • National or regional offices for the condition' • Local Library • Provided by physician or healthcare funder	• Internet • Local Library • Word of Mouth • Family Networks • Local organizations
Process for accessing resource	Must apply at a local SSA office for SSI EPSDT is a set of standards for care and not actually a resource that is provided (one must be eligible for Medicaid for legislative standards to apply)	Varies from state to state Some state programs such as Medicaid Waivers have existing waiting lists prior to accessing services. Families may need to meet a financial and or medical eligibility requirement. Some state waivers require a cost neutrality factor.	Process for accessing each program or support varies based upon service desired. However, active military can use Military One Source as an Employee Assistance Program benefit to assist in facilitating programs and resources.	Correspondence Application process - varies across organizations May require physician documentation of specific condition	Formal and informal application processes varies across sponsoring organization Sometimes requires documentation from a healthcare provider or other entity
Barriers for families in identifying and finding resource	Application process May require physician documentation Locations of local offices Lack of knowledge regarding potential resource Income level too high Application process requires persistence and may require multiple appeals for award	Application process Varying eligibility requirements (financial, medical, geographic) Some Medicaid programs for special groups have limited slots and lengthy waits for services Lack of knowledge regarding potential resource Information found on websites is global and family may not realize they do not quality until they have already gone through the process.	Service availability and extent of support may depend on the individual's status within the military. Some qualifiers include active vs. retired status, reserves or branch of service.	Application process Acceptable documentation of condition particularly if diagnosis is unclear Lack of knowledge regarding potential resource	Application process Lack of knowledge regarding potential resource Documentation from healthcare provider Applicant may not meet specific target criteria for accessing the service (ex. geographic, age, culture, religious affiliation, etc.)

		State programs vary from state to state in regards to eligibility, benefits and service delivery			
Strategies that can be incorporated in a new model design to optimize use of resources	Educate families regarding the potential resource Assist families in facilitation of application process and identification of local SSA office Educate families regarding appeal process	Educate families regarding the potential resource Assist families in facilitation of application process and identification of local state offices Educate families regarding appeal process	Encourage the use of Military One Source and develop relationships between family and a coordinator from One Source. See Military One Source Report for more specific recommendations) Encourage families to participate on family networking forums (i.e. STOMP or discussion forum through Military HOMEFRONT) to encourage dialogue regarding experiences of what works and doesn't work when working with systems to access services. Families who have experience working through various systems may be willing to share their knowledge to assist other families in similar situations.	Access to information related to condition specific resource centers Education for families related to how to identify resource opportunities	Access to information related to local resources. Education for families related to how to identify resource opportunities within their local community

ATTACHMENT I

Case Management
Care Management
Care Coordination

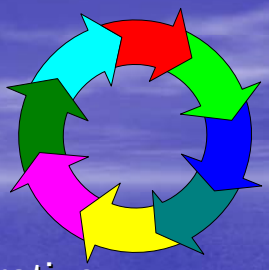
A Matter of Perspective

Prepared by,
The Coordinating Center
August 10, 2005

Otherwise known as.....

- Case management
- Care management
- Benefits management
- Utilization review management (UR)
- Case worker
- Care coordination*

Definition



- Case management is a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality, cost-effective outcomes

CMSA Standards of Practice for Case Management, 2002

Setting Industry Standards

- **Commission for Case Management Certification (CCM)**
- **Certification of Disability Management Specialists (CDMS)**
- **Commission on Rehabilitation Counselor Certification(CRCC)**
- **National Association of Social Workers (ASW-C)**
- **CMSA (Case Management Society of America)**
  - **Local and National organization for case managers**
- **URAC**
  - **Set standards for organizational level accreditation in the following areas**
    - HIPAA certification
    - Case Management
    - Claims Processing
    - Consumer Directed Health
    - Core Accreditation
    - Credentials Verification Organization (CVO)
    - Disease Management
    - Health Call Center
    - Health Network
    - Health Plan
    - Health Provider Credentialing
    - Health Utilization Management
    - Health Web Site
    - HIPAA Privacy
    - HIPAA Security
    - Independent Review
    - Workers' Compensation Utilization Management

About URAC

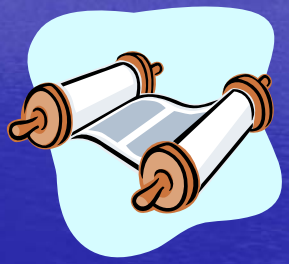
- Nonprofit, independent organization, is well known as a leader in promoting health care quality through certification and accreditation programs.
- Offers a range of quality benchmarking programs and services
- Ensures that all stakeholders are represented in establishing meaningful quality measures for the entire healthcare industry

URAC website

http://www.urac.org/

URAC Core Standard's address

- Organizational framework
- Information system
- Delegation
- Qualifications, licensure, scope of practice
- Policies and procedures
- Quality program
- Consents
- And more…….



Standards at a Glance, Accreditation Program Guide for Case Management Standards, Version 2.0, URAC 2002

Settings for Case Management Services

- Hospitals and Integrated Delivery Systems
- Corporations
- Public Insurance
  - Medicaid and Medicare
- Private Insurance
  - Workman's Comp
  - Disability Liability
  - Auto
  - Accident and health
- Managed Care Organizations
- Independent Case Management Companies

- Government Sponsored Programs
  - Military
  - Correctional Facilities
  - Public Health
- Provider agencies
  - Mental health facilities
  - Home health
  - Ambulatory and Day Care
  - Geriatric services
  - Long term care services
  - Hospice
  - Physician practices
  - Disease management companies

Functions of Case Management

- Assessment
- Planning
- Facilitation
- Advocacy

CMSA Standards of Practice for Case Management, 2002

Assessment

- Case identification (screening)
- The gathering of relevant, comprehensive information from the healthcare team and other appropriate individuals

CMSA Standards of Practice for Case Management, 2002

Planning

- Develop a Plan of Care in conjunction with the individual, family and other healthcare team members
- The goal is to develop an appropriate and fiscally responsible plan to enhance quality, access, and cost-effective outcomes.
- Goal setting
- Contingency plan in the event of health or service complications
- CM should initiate modifications to adapt to changes over time and settings

Facilitation

- CM should actively promote, coordinate, communicate and collaborate on behalf of the individual/ family, PCP, members of the health care team, the payer and others such as legal, educational and spiritual communities
- Reconcile differing points of view to ensure wishes of child/ family are understood
- Facilitate education and prevent risks behaviors to promote optimal wellness

Advocacy

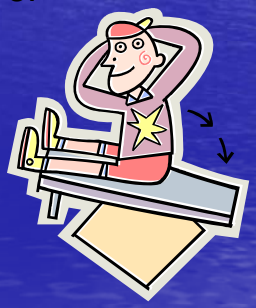
- Respect beliefs, value system, and decisions of the child/family
- Incorporate self determination
- Support and educate the child/ family to achieve self advocacy whenever possible

Models for Medical Case Management

Complex Care Management
Paradigm Health
Annual Report, 2004

Population Health Model

- Basically healthy individuals who need routine preventative care and short-term treatment for illnesses or injuries
- Third party payers may use this model to minimize risk of more serious illness that attributes to higher health care costs



Disease Management Model

- Individuals with troublesome but manageable chronic illness who need ongoing coordinated care to prevent worsening, but who then function well
- Usually an illness that has a higher level of prevalence in the general population and if managed proactively can yield significant reduction in cost of care and in quality of life
- Often identify potential participants through claims review process.

Individual Model

- Individuals with serious, possibly life threatening chronic conditions who need continuous care, pain and symptom management, advance care planning, assistance with ADL's, suitable housing, and whose family caregivers need additional support.

Social Model

- Often referred to as "case worker"
- May be seen most often in Social Services arena, criminal justice, and educational system
- Often used in the Developmental Disabilities World and sometimes referred to as "service coordination"
- Less emphasis placed on certification and/or professional licensure

The Care Coordination Perspective

- Care Coordination implies a partnership with the person/family and is based in person/family centered philosophy and practice
- It is based on a key concept that health is only one component of the process
- It relies on the idea that planning begins with the person; find the resources to meet the person's needs using all community avenues.

2003 Case Management Salary Survey

- Salaries vary based upon geography, setting, caseload and experience
- Salary range from $39,000 West suburban areas to $59,000 in the Pacific rural areas

ADVANCE for Providers of Post-Acute Care

May/ June 2003, p. 51

www.advanceforPAC.com

Caseload and Setting

- Case managers who work in managed care, medical groups or worker's compensation report highest caseloads of greater than 60.
- Lowest caseloads are reported in rehab facilities (22), hospice (23) and business owners (25)

ADVANCE for Providers of Post-Acute Care

May/ June 2003, p. 54

www.advanceforPAC.com

Current Issues in Case Management

- Demonstrating and Improving Outcomes of Case Management
- Consumer Directed Trends
- Chronic Care Management
- Education
- CM/Physician Relationship
- Cultural and Linguistic Competency
- Legal & Ethical Issues
- CM Legislation
- Shifting CM roles and job functions
- Growing need for more CMs

Trends Impacting Case Management

CMSA, 2002

National Conferences Specific to Case Management

- Case Management Society of America (CMSA)
- Medical Case Management Conference (MCMC)

APPENDIX 9

Index to Standards and Documentation for CHI PACC

Required Components: to develop local programs of all inclusive care of children/adolescents who are diagnosed with life threatening conditions and family members

Goal: to expand access to curative and palliative services

CHI PACC Standard	Topic
I. COMPREHENSIVE CARE, INTERDISCIPLINARY TEAM	Creation of a continuum of care integrating provider organizations, community-based organizations, professionals and volunteers into one unified interdisciplinary team, providing any medical nursing, psychosocial or spiritual service needed for the child or family.
A. Access to Care	Children and adolescents eligible for care in the Military Health System diagnosed with life-threatening conditions and the members of their families have ease of access to a comprehensive, coordinated, competent continuum of care in their communities.
B. Family-Centered Care	Care in the Military Health System is consistently child/adolescent oriented and family-centered in its philosophy, values, practices, and operation. Family-centered care seeks to support and enhance the life-experience and its quality for each child/adolescent and their family as defined by their culture, values, beliefs, priorities, circumstances, choices and structure.
C. Ethics	Disperse E1-E7 through other categories.
D. Interdisciplinary Team	Children/adolescents living with life-threatening conditions and the members of their families have a wide range and intensity of ongoing hopes and changing needs requiring care. This complex need for care requires the expertise and competence of many disciplines, perspectives, and skills working together with the family as an integrated, comprehensive, coordinated team to provide effective care.
E. Counseling and Supportive Care	Children and adolescents with life-threatening illnesses and their family members must have access to a comprehensive, coordinated, competent continuum of counseling and supportive services to assist them with the physical, emotional and spiritual issues, interpersonal dynamics and psychosocial dimensions of their expertise.

F. Bereavement Services	Bereavement services are supportive and/or professional services following the child's/adolescent's death for a period of time, with the overall goal of assisting the family members in reintegrating themselves into the communities of which they are a part and to find their long-term support in their communities.
G. Care Coordination	Care coordination is a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality and cost-effective outcomes.
H. Education for Health Care Providers & Families	
II. CURATIVE/PALLIATIVE CARE SIMULTANEOUS	Integration of curative care with palliative care and community-based supportive services.
A. Goals of Care	The goals of care establish the integrated treatment of the disease or life-threatening condition along with the palliative care plan of care and array of services to be provided. All medical treatment and palliative care goals are developed in collaboration with the child/adolescent and family.
B. Comprehensive Assessment Process	Comprehensive interdisciplinary assessment is used to insure that the goals of care and plan of care are based on needs identified as important to the child/adolescent and family. This assessment process is ongoing as needs, circumstances, and hopes change during the course of care in response to the progression of the child's/adolescent's life-threatening condition and its symptomology.
C. Plan of Care	Plan of Care is a comprehensive document incorporating the individual child/adolescent and family goals and services addressing the medical, nursing, psychosocial, spiritual, educational, emotional, and practical concerns and needs.

D. Symptom Management	
III. CARE FROM POINT OF DIAGNOSIS WITH AN IDENTIFIED CARE COORDINATOR	Establishment of a system of comprehensive care providing a wide range of interdisciplinary services available from the time of diagnosis, onset, or time of referral, through the attainment of cure/remission, the graduation into an adult program of care, or if necessary, the provision of bereavement counseling.
A. Continuity of Care	Define MHS context - capture transition issues.
B. Assignment to Care Coordinator	(replaces "admission process")
C. Research and Evaluation	(include family satisfaction and cost effectiveness here)
D. TRICARE Framework	(replaces "governance and administration")
IV. ADEQUATE AND FLEXIBLE FUNDING	Redistribution of funding in order to increase the range of services available in the community and to ensure that the funds follow the child/family into the most appropriate treatment setting.